

Dignity in continence care in people with dementia and incontinence: Translating principles that protect dignity

Dignity in continence care MOOC

Final Report

Prepared by:

National Ageing Research Institute
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Contact:

Professor Joan Ostaszewicz

M +61 441 975 440

E j.ostaskiewicz@nari.edu.au

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Project Team: Professor Joan Ostaszkiwicz, Dr Jessica Cecil, Elizabeth Watt, Dr Elizabeth Pascoe

Associate Investigators Professor Briony Dow, Professor Elizabeth Beattie, Professor Alison Hutchinson, Associate Professor Michael Murray, Dr Anita Goh

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ABBREVIATIONS

NARI	National Ageing Research Institute
MOOC	Massive Open Online Course
PAG	Project Advisory Group
CI Group	Chief Investigators Group
RACF	Residential Aged Care Facility
RN	Registered Nurse
EN	Enrolled Nurse
ICIQ- Cog-P	Measure of incontinence-related bother
ICIQ-Cog-C	Measure of care efforts associated with cognitive impairment and incontinence
EQ-5D-3L	Generic measure of health-related quality of life version 3L
ZBI -12	Short Form Zarit Burden Interview
QoL	Quality of Life
T1	MOOC pre-education online survey (time 1)
T2	MOOC post-education online survey (time 2)
M	Mean
SD	Standard Deviation
N	Population size
n	Sample size
α	Cronbach's alpha

EXECUTIVE SUMMARY

The aim of the project titled ***‘Dignity in continence care in people with dementia and incontinence: Translating principles that protect dignity’*** was to develop, disseminate and evaluate a Massive Online Open Course (MOOC) about dignity-based continence care. People living with dementia and incontinence are at risk of breaches to their personal dignity during continence care interactions, particularly when in formal care settings. The ways carers interact with people who require support to maintain continence and manage incontinence either upholds or diminishes that person’s dignity.

A search of literature conducted by the project team identified a lack of information and guidance to support carers cope with the range of psychological and physiological aspects of living with incontinence or caring for a person with incontinence, particularly when they also live with dementia. Existing guidance is underpinned by the goal of cure, which may be of little assistance to carers dealing with the day-to-day continence caregiving.

Arguably, information about providing continence care to people with dementia should be developed in partnership with consumers and their caregivers. To this end, the project team engaged people living with dementia, their family carers, and professional carers to meet to discuss their shared and unique experiences about living with incontinence, and about continence caregiving in the context of a dementia diagnosis. The group consisted of three community-dwelling people with self-reported mild dementia and incontinence; eight family carers who supported them to manage incontinence or maintain continence; and eleven nursing home employees with experience of assessing or providing continence care to people with dementia, most of whom also had personal experience of caring for a family member living with dementia. Discussions with the group yielded several recommendations about caring for a person with dementia and incontinence.

The research team interpreted the information in collaboration with instructional designers at Deakin University, Global Studio who had experience in the design and delivery of FutureLearn MOOCs. Although MOOCs have been available since 2008, an extensive search failed to identify a MOOC that addressed the topic of caring for a person living with dementia and incontinence.

The brief for the MOOC was to ensure it was written in an accessible language for members of the general public, that it includes navigational cues, opportunities for peer interaction and to ask questions of facilitators, and for users to share knowledge and experiences. Links to organisations and other resources about salient topics or further information were required, as well as an evaluation process with optional quizzes and a certificate of completion offered on successful completion of a final quiz. A nominal fee is built into the cost of obtaining a certificate of completion (if required) to cover the cost of facilitation, which was undertaken by a member of the project team.

The MOOC was conducted up to three times, monitored, facilitated, evaluated, and modified to ensure it was fit for purpose. MOOC participants were invited to opt in to a pre and post education survey and telephone interview to evaluate its appropriateness and effectiveness in helping carers of people living with dementia address the physical, psychological, and psychosocial aspects of incontinence, thus optimising safety, respect and dignity for both parties.

The development of this type of knowledge translational resource is particularly timely given the current demand for online learning and support, and the need to respond to the increasing incidence of dementia and the needs of an ageing population.

1. BACKGROUND

The prevalence of incontinence with dementia

People with a diagnosis of dementia are three times more likely to experience urinary incontinence, and four times more likely to experience faecal incontinence than people without dementia. Specifically, the relative risk of developing urinary incontinence is 2.03 (95% CI 1.73–2.36) in people with MMSE < 24 compared to MMSE > 24 (Grant et al., 2013). The prevalence of incontinence in people with a diagnosis of dementia living in residential aged care homes, is even higher than in the community. The Australian Institute for Health and Welfare (AIHW) reported 69.4% of people living with dementia in aged care homes in Australia experience three or more episodes of urinary incontinence a day and 45.7% experience more than four episodes of faecal incontinence per week (AIHW, 2011). The most common type of incontinence in residential aged care homes is termed 'disability incontinence' (Jerez-Roig et al., 2016), which is the 'complaint of urinary incontinence in the presence of a functional inability to reach a toilet/urinal in time because of a physical impairment, (e.g. orthopaedic, neurological) and/or mental impairment (D'Ancona, et al. 2019, p. 436). This key finding underlies the importance of carer-led interventions that compensate for peoples' disabilities to optimise their continence.

The aetiology of incontinence in dementia

Incontinence has a multifactorial aetiology in older people and in people with dementia (Wagg et al., 2017). Older people living with dementia are just as likely as those without dementia to experience incontinence because of physiological age-related changes to the bladder, bowel, urethra, and prostate, as well as factors outside the lower urinary tract. The latter include conditions such as diabetes, congestive heart failure, degenerative joint disease, constipation, faecal impaction, and neurological conditions such as stroke and Parkinson's disease. Many medications also contribute to incontinence (Wagg et al., 2017). Another contributing factor is the physical and social environment (Wagg et al., 2017). However, having a diagnosis of dementia creates additional challenges for the person by disrupting their ability to recognise the need to go to the toilet, communicate their toileting needs, locate and recognise the toilet, and use the toilet properly (Wagg et al., 2017).

Challenges associated with continence care

In Australia, one in five primary carers (18.7%) provide assistance with toileting activities (Australian Bureau of Statistics [ABS], 2018). It is important to note that **'not all of the strategies carers trial are acceptable or understood by the person with dementia'**. Carers describe a range of problems related to supporting the person to remain independent in toileting, including managing behavioural challenges, and containing and managing incontinence. Issues associated with lower urinary tract symptoms and toilet problems in caring for the person with dementia are specifically identified as having a significant impact on caregiver burden (Kamiya et al., 2023). Family carers of people living with dementia and incontinence experience a trial-and-error approach to continence care and a lack of information and support to help them in their caregiving role (Bliss et al., 2013; Cole et al. 2022; Drennan et al., 2011; Cole & Drennan, 2019; Juliebø-Jones et al., 2021; Murphy et al., 2021; Mullins et al., 2016). Indeed, incontinence is the mettle that they must grasp and manage if they are to support caregiving at home (Upton & Reed, 2005).

In formal care settings, it is hypothesised that discordance between carers and care recipients about the best ways to manage incontinence can trigger distressed responses (Ostaszkievicz, 2018). For example, if poorly managed, care interactions may escalate into coercive or harmful care and violations to care recipient's dignity and increase the risk of physical harm to both parties (Ostaszkievicz, 2018). This is likely to further relate to the ethical challenges formal carers' experience when having to choose between upholding the rights of the resident to decline assistance, with the responsibility to protect the resident from harm (Ostaszkievicz et al., 2014). Indeed, this scenario was described by the Royal Commission into Aged Care Quality and Safety which cited frequent examples of a lack of dignity in the form of neglect of personal care and verbal abuse: i.e.,

Nursing staff acting in an intimidating manner, deferring or failing to provide residents with toileting assistance, aggressively washing a resident's genital areas and failing to address their need for hygiene assistance (Ostaszkiwicz et al., 2014). Although the Australian Government has subsequently responded to most of the recommendations of the Royal Commission into Aged Care Safety and Quality and regulation of the aged care sector has been strengthened, the management of incontinence by people receiving aged care services and supports has received scant attention (Royal Commission into Aged Care Quality and Safety, 2021). The implications of this oversight for family carers in particular are likely to be significant, potentially increasing the risk of abuse and that the person with dementia is admitted to residential aged care.

The impact of incontinence

The impacts of incontinence are considerable, increasing older peoples' risk of falling in residential aged care homes and in the community (Hasegawa et al., 2010; Schluter et al., 2018) their risk of developing incontinence-associated dermatitis that leads to pressure injuries (Van Damme et al., 2017) and reducing their quality of life (Xu & Kane, 2013). In residential aged care homes, having urinary incontinence is also an independent predictor of death (Damián, et al., 2017, Moon & Hong, 2020). The negative effects of incontinence also extend to family carers who find themselves having to engage in intimate care activities that can alter the nature of the relationship (Cole et al. 2022). International research involving qualitative interviews with family carers of people with a diagnosis of dementia suggests managing incontinence adds to carer burden (Drennan et al., 2011; Murphy et al., 2021), with caregiver burden highlighted as being pronounced among carers managing the day-to-day continence issues of the person living with dementia (Lodewyk et al., 2022; Kamiya et al., 2023).

Part of the burden associated with continence caregiving could relate to the additional time required. A survey of 7,433 people aged 70 and older from a nationally representative sample in the US found severe urinary incontinence consumes considerably more time than caring for a person without incontinence (Langa et al., 2002). A multivariate regression analysis found urinary incontinence was associated with the greatest intensity of informal care: an additional 1.3 hours per day for men and 40 minutes per day for women. Specifically, men with severe urinary incontinence required 16.6 hours of care per week compared to 7.4 hours for men who are continent whilst women with severe urinary incontinence required 10.7 hours of care per week compared to 5.9 hours for women who are continent (Langa et al., 2002).

The increased risk of institutionalisation

Several studies demonstrate an association between incontinence and institutionalisation as well as an association between dementia and institutionalisation. Incontinence predicts institutionalisation independently of other factors such as age, low self-rated health, or functional impairments (Andel et al., 2007, Holroyd-Leduc et al., 2004). A US study found around 10% of male and 6% of female admissions to residential aged care are attributable to urinary incontinence alone (Morrison & Levy 2006). As the severity of incontinence increases, so does the risk of being admitted to a residential aged care home (Carvalho et al., 2020). Once in a residential aged care home, residents with a diagnosis of dementia are more likely to lose continence at a more rapid rate than those without dementia (Wagg et al., 2016).

Gaps in information about caring for a person with dementia and incontinence

A search of peer review and grey literature identifies a lack of information and guidance to support carers cope with the range of psychological and physiological aspects of living with incontinence or caring for a person with incontinence, particularly when they also live with dementia. A systematic review by Edwards et al. (2021) of continence care for people living with dementia also identified significant gaps in training, concluding that training must be developed in partnership with consumers and their caregivers. The focus of guidelines about incontinence is the assessment and treatment of the condition, rather than care. Similarly, the focus of guidelines about dementia is on screening for early diagnosis, cure, and non-pharmacological and

pharmacological management of behaviours. Hence, they are underpinned by the goal of care that may be of little assistance to carers dealing with the day-to-day management of continence caregiving. It was against this background that researchers at NARI identified the need to design accessible content to equip carers with the knowledge and skills to provide continence care in a way that upholds the dignity of the person with dementia.

The Dignity in Continence Care Framework

Researchers at NARI have an established program of research on continence care which promotes dignity as an important goal of care. In 2017, Ostaszkievicz published a paper describing '*The Dignity in Continence Care Framework*' which was developed after extensive stakeholder consultation, robust research, and an integration of contemporary biomedical understandings about incontinence with theoretical concepts from the disciplines of nursing, psychology, and sociology (Ostaszkievicz, 2017). The framework promotes continence care that is informed by the person's or proxy's beliefs and values about continence care practice that make them feel safe, respected and, most importantly, dignified. A recent concept analysis conducted by Ostaszkievicz and colleagues (Ostaszkievicz et al., 2020) revealed the attributes of dignity-protective continence care are characterized by privacy, respect, autonomy, empathy, trust, and communication. The team anticipated drawing on this body of research to design information to support carers address the continence care needs of people with dementia in both formal and informal settings.

The use of a digital educational platform

The use of digital platforms for the development and distribution of educational resources and support for carers of people living with dementia has grown substantially over the past ten years (Davies et al., 2019; Davies et al., 2020; Hopwood et al., 2018; Whitlatch & Orsulic-Jeras, 2018). According to the Australian Bureau of Statistics (2018), 61% of older Australians (aged 65 years and older) used the internet in the previous 3 months. While internet use decreased with age, 74% of those aged 65-74 years and 48.5% of those aged 75-84 years used the internet.

An internet-based resource has the potential to meet the needs of carers where there are gaps in service provision and it can be a more flexible resource for and carers who may find it difficult to access information and support outside of the home due to their caring responsibilities (Davies et al., 2019). A focused internet-based resource can bring together information from a variety of sources into an easily accessible, streamlined, and curated resource which can save carers time and effort and ensures that the information or resources are of high quality.

Internet based educational and support resources have been found to have positive impacts on the well-being, depression, anxiety, and perceived burden in carers of people living with dementia (Davies et al., 2020; Hopwood et al., 2018; Leng et al., 2020). While there is no research that specifically evaluates an internet-based intervention for carers of people living with dementia and incontinence, there is evidence that internet-based information is an effective tool for health education focused on interventions to treat continence (Firet et al., 2022; Wadensten et al., 2021). MOOCs have been found to be an effective method for health education on a variety of topics (Farrow et al., 2022; Mansilla et al., 2021) and have the potential to enable health education to be accessible by a large, diverse audience (Liyanagunawardena & Aboshady, 2018).

Co-design methods

People living with dementia, particularly those in the later stages, have historically been excluded from participatory research (Goh et al., 2022), limiting their opportunities for active involvement in shaping interventions and services. In its Statement on Consumer and Community Involvement in Health and Medical Research (2016) (the Statement), the National Health and Medical Research Council promote the involvement of consumers as active partners in research. It is recognised that their involvement can lead to quality research

that meets the needs of the community and promote the translation of research into improved policy and practice.

The use of co-design methods has emerged as a powerful means of facilitating meaningful involvement of people living with dementia in research and enabling their active participation and contribution to research. In theory, co-production can redistribute responsibility, power and control between researchers and key stakeholders (Ward et al., 2018).

In traditional research, the focus often lies on experts and researchers who act as the primary decision-makers in shaping interventions. However, co-design involves individuals who directly experience the problem at the centre of the design process. As individuals who experience the problem are involved in the planning, design, development and review of interventions, the resulting solution is more likely to address their needs and concerns and as a result, facilitate the production of interventions that are more likely to be contextually relevant and effective. By embracing the diverse voices and valuating the contribution of all participants, co-design fosters a holistic understanding of the problem and facilitates development of person-centred, evidence-based interventions that effectively address user needs. At its core, co-design as a research methodology recognises diverse perspectives, experiences and expertise and advocates for active participation and collaborative discussion.

One widely recognised methodology employed in co-design that has shown success in involving individuals living with dementia is the World Café approach (Goh et al., 2022). The World Café approach provides a dynamic and interactive platform where participants are brought together in small groups, often in a comfortable environment reminiscent of a café setting, to engage in focused conversations on specific issues (Lohr et al., 2020). This cafe-style social context provides a structured yet flexible space that encourages equitable participation, allowing for participants to engage in meaningful open and inclusive conversations to share, discuss and collectively generate ideas collaboratively in a non-threatening manner (Fouche & Light 2011: Lohr et al., 2020).

Within the World Café setting, all participants are recognised as experts of their own experience and encouraged to contribute their knowledge and insights (Goh et al., 2022). This approach empowers individuals to contribute their own unique perspectives, there is no pressure to reach a consensus, fostering an environment where diverse perspectives and discussion is encouraged, promoting a free flow of ideas and the exploration of diverse viewpoints and experiences to generate a comprehensive overview of the subject matter.

By harnessing the power of diverse perspectives, the World Café method holds great potential for generating actionable insights and facilitating positive change in research contexts. It offers space for participants to engage in deep meaningful conversations, build upon each other's ideas and collectively explore innovative solutions. Through this collaborative process, the World Café method encourages the co-creation or co-design of interventions that are contextually relevant, effective and resonate with the needs and preferences of the target population (Goh et al., 2022). Despite the growing application of co-design in research, previous co-design studies are predominately outcome focused e.g. designing products, programs or interventions that typically report on the results of co-designed outputs, and little that provide detailed guidance on the co-design methodology itself, such as how co-design activities were conducted or facilitated (Goh et al., 2022).

2. PROJECT AIM

To co-design and evaluate a Massive Open Online Course (MOOC) to support carers of people living with dementia and incontinence.

3. PROJECT OBJECTIVES

1. Involve people living with dementia and continence care needs: informal carers (i.e., family carers); and formal carers (i.e., aged-care direct care employees) in the design of a MOOC that is based on the *Dignity in Continence Care Program*.
2. Engage experts in instructional design in the process of developing the MOOC.
3. Convening the MOOC, monitoring, facilitating, evaluating, and modifying it to ensure it is fit for purpose.
4. Collect, collate, and analyse MOOC participants support-related quality-of-life (QoL) data.

4. METHODOLOGY

4.1 Study Design

A mixed methods study informed by the principles of co-design was conducted over two years in three phases:

- Phase 1: Establishment
- Phase 2: Design and testing
- Phase 3: Dissemination, facilitation, and maintenance

Phase	Time	Deliverables	Reporting/Resources
1. Establishment phase	July-Dec 2021	Establish CI group and project team	• Written report: recommendations and amendments to the DICCP • Written report: MOOC Educational Content
		Establish PAG	
		Receive ethics approval and project governance	
		Conduct 4 PAG meetings	
		Develop content for the MOOC and get feedback at each PAG meeting	
2. Design and Testing	Jan- July 2022	Develop the MOOC with the online education provider (FutureLearn)	• Resource: MOOC • Report: PAG/community feedback on the MOOC
		Conduct and record video interviews to use as MOOC content	
		Receive PAG feedback on the MOOC	
		Receive community feedback on the MOOC	
		Review MOOC and make revisions	
3. Dissemination, facilitation, and maintenance	July2022- June 2023	Deliver and moderate the MOOC twice in 2022 and once in 2023	• Report: Evaluation of the MOOC • Resource: MOOC
		MOOC Evaluation - Pre-education survey - Post-education survey - Post-education interviews	
		Analyze qualitative and quantitative data	
		Review and make final revisions to the MOOC	

4.2 Ethics

The project was approved by the Austin Health Human Research Ethics Committee on 4th October 2021 HREC Reference Number: HREC/77685/Austin-2021 / Austin Health SITE REFERENCE Number: ND 77685/2021 (see Appendix 1). Reciprocal approval was provided by the Deakin University Human Research Ethics Committee May 20-022 Ref 2022-140 (see Appendix 2). This included approval related to the recruitment processes, consent, data collection procedures, participant safety and handling of withdrawals, involvement

of individuals with cognitive impairment, participants in other countries, disclosure of data to a third party, risks associated with COVID-19, management of potential participant discomfort and distress, collection of sensitive data, data security and handling, confidentiality of data. All materials were approved.

4.3 Phase 1. Establishment (Months 1-6)

Phase 1 involved consulting with people with dementia and continence care needs; informal carers (i.e., family carers); and formal carers (i.e., aged care direct care employees) in the development of informational content for the MOOC. This was done by establishing a small Project Advisory Group (PAG) with representatives from the following three stakeholder groups:

- i. Family carers who support people living with dementia (any stage) to manage incontinence or maintain continence.
- ii. Community-dwelling people with self-reported dementia and continence care needs
- iii. Aged care employees with experience of assessing or providing continence care to people with dementia (any stage) in a residential aged care home (i.e., RNs, ENs, Personal Care Assistants).

Information about the opportunity to join the PAG was disseminated through relevant social and media platforms and outlets. This included recruitment through NARIs network of people who had expressed an interest in participating in research, as well as advocacy groups (i.e., COTA, Carers Victoria) and organisations such as Dementia Australia, and the Continence Foundation Australia. Registered and Enrolled Nurses, and Care Assistants with experience of assessing or providing continence care to people with dementia in an aged care home were recruited through information disseminated by professional and union groups such as the College of Nursing, the Australian and Nursing and Midwifery Federation and Health Services Union. Members of the PAG met online five times over six months (2-hour meetings). They:

- Advised on the content of a course to support carers of people living with memory problems who require continence care.
- Commented on the suitability of current public information on this topic.
- Discussed the appropriateness of prioritising dignity as the main goal of care in the proposed course.
- Reviewed progress and commented on drafts of the course.

The PAG meetings were conducted online using Zoom software. This was done initially to meet COVID lockdown requirements, however it also enabled more carers to attend as they were able to organise short term care assistance for their family member and did not need to travel. It also enabled several carers to attend who lived in regional and rural areas. Meetings were conducted formally in that there was an agenda, a PowerPoint presentation and relevant documents sent to members prior to each meeting and meeting notes were sent after meetings.

In the early meetings, members were divided into groups within Zoom to ensure that all members had an opportunity to contribute and comment. The discussion groups had a list of questions to prompt discussion and were led by a member of the project team. The facilitator's role was to guide, encourage and clarify discussion points raised by PAG members somewhat like the role of a facilitator in a focus group. The outcomes of the discussion groups were treated as 'data' that could be analysed using content analysis (Bengtsson, 2016). In approaching the content from the discussion in this way, the project team aimed to reduce the volume of information that was obtained, identify groups and categories or themes within the information and ultimately to represent the information from PAG members in a true and accurate manner and increase the trustworthiness of the outcomes (Bengtsson, 2016).

During the early meetings the two group facilitators took detailed notes of the PAG group discussions. These notes were typed as soon as possible after the meeting to accurately capture the context and meaning of the PAG members. Additional information was also invited and received via email from individual members who

could either not attend the meeting or by members who felt they had more to contribute. Some chose to write their contribution, and some sent in a voice recording. These contributions were added to data from the discussion groups.

By being involved in the group discussion process and then by reading and rereading the points raised, each facilitator was then able to get a sense of the meaning of the points raised by the group members (Bengtsson, 2016) and then begin to organise these points into themes. The two facilitators then met and compared the findings from their respective groups. The data was discussed, compared, and re-compared. Some themes were merged or extended, and subthemes were identified. The themes eventually became the weekly topic headings, and the subthemes became the topic content headings.

The findings from the discussion groups were sent back to PAG members after each meeting and further comment was invited and received. Additional information was incorporated into the discussion group findings document. This process was repeated until we developed a detailed outline of the MOOC which was contextualised to address the needs of carers of people living with dementia and incontinence and agreed upon by PAG members.

4.4 Phase 2: Design and testing (months 7-14)

During stage two, the research engaged with educational designers at Deakin University, Global Studio with experience in the design and delivery of FutureLearn MOOCs. FutureLearn is a Massive Open Online Course learning platform, and as of June 2023 included 260 universities, specialist organisations, including government and non-government partners. The project team were responsible for determining the content, learning design and technical platform.

The brief for the MOOC was to ensure it was written in an accessible language for members of the public, that it includes navigational cues, opportunities for peer interaction and to ask questions of facilitators, and for users to share knowledge and experiences. Links to organisations and other resources about salient topics or further information were required, as well as an evaluation process with optional quizzes and a certificate of completion offered on successful completion of a final quiz. A nominal fee is built into the cost of obtaining a certificate of completion (if required) to cover the cost of facilitation, which was undertaken by a member of the project team.

The FutureLearn Platform

FutureLearn is an online education provider that offers online courses, popularly known as MOOCs or Massive Open Online Courses, from top universities and other partner organisations in the United Kingdom and around the world. FutureLearn is owned by a private company, Global University Systems. Deakin University (Melbourne) is a partner organisation and have a learning design team that is skilled in the use of the learning platform.

Currently, FutureLearn has more than 2000 online courses created by these partner institutions. They offer a variety of courses including short courses, subjects, ExpertTracks (specialist courses), microcredentials and online degree courses. Many courses are free to access for a limited time. If the learner wants unlimited access, or access to tests or exams to earn a subject or course certificate, they need to pay a fee. The features of a MOOC make them accessible to a diverse population of learners who may not be able to access face-to-face learning opportunities (Rizvi et al., 2020). FutureLearn MOOCs are highly rated by learners; 4.6 (out of 5) average for all courses (FutureLearn, 2023a). Learners who wish to obtain a certificate of completion, must upgrade their access by paying a fee (either as a one-off fee or a subscription), mark of 90% of the course steps as complete, and attempt all test questions, achieving a score of 70% or above. Upgrading also gives the learner unlimited access to the course materials. The fee structure for FutureLearn courses is available in Appendix 3.

FutureLearn is a social learning platform. Learners are encouraged to 'chat' with each other, learn from each other, and learn flexibly wherever and whenever it suits them. FutureLearn courses are divided into weeks, each one built from a sequence of straightforward steps that are easy to navigate. Each week consists of a variety of learning activities (tasks), including videos, content to read, links to relevant internet resources, summary sheets, quizzes and comments or discussions. This enables learners to interact with other learners, ask questions, clarify their thinking, and add to a discussion of a topic. Learners can track their learning by marking where they up to but can move forward and backward through the learning materials as they choose. In a similar way to social media platforms, learners can 'follow' and filter discussions and comments. In this way incidental learning from peers can take place. Students and educators can reply to each other's posts but cannot contact them personally or privately.

Each week is structured in a similar way, so learners quickly become familiar with the structure. Each week is completed with a summary of the key ideas and principles covered and an outline of what will be covered in the following week. This signposting helps to develop a narrative and allows learners to see where they've come from and where they're going (FutureLearn, 2023b). At the end of each week learners complete a quiz which enables them to check how well they have understood key points before moving on. The quizzes are not scored but learners get feedback and hints as they move through the questions. Award courses will also have other assessment tasks to assess their learning.

The FutureLearn platform has built in learner support to give feedback or report a problem. The feedback button gives the learner options of accessing a 'knowledge base' or looking through 'frequently asked questions', including those submitted by other learners. Alternatively, the learner can submit a technical query or problem to the FutureLearn team. Similarly, the platform has built in features to enhance the on-line safety of learners, moderators and FutureLearn staff. Where learners have concerns about another learners' comments, they can press a 'report' or 'flag' button which alerts FutureLearn staff to review the comment, a process of moderation. FutureLearn employs a moderation agency that works on a shift basis, around the clock, every day of the year, to review comments that have been reported using the flag button (FutureLearn, 2023c). The learner is also prompted to write a note explaining why they are concerned. This process is done anonymously; the person who wrote the concerning comment will not know who has reported them. A similar process can be undertaken to report an educator or to report online bullying. FutureLearn has a code of conduct which every learner agrees to when registering with FutureLearn (FutureLearn, 2023d).

Learning design

The project team used a generic high level learning template to outline the proposed course learning outcomes, the structure in modules (weeks), module title, module learning outcomes, module key concepts, an outline of the proposed focus of the video or case study for the week, an outline of key learning activities, and proposed links to internet or other resources. The final version of this document was reviewed and agreed upon by the PAG committee and the Chief Investigator Group.

The next stage in the design process involved writing the content for each of the modules. The development of the content was primarily informed by the feedback from the PAG group. Additionally, the content was informed by knowledge gained from the literature review completed earlier in the project, and from the extensive clinical and academic knowledge and experience of several members of the project team. As the content was developed it was reviewed by members of the project team and revised where necessary. The content, resources, and proposed learning activities were fully mapped out before the project team met with the educational design team.

The project team met face-to-face with the educational design team from Deakin Learning Futures - Global Studios, following changes to COVID lockdown rules in March 2022. The design team consisted of a Senior educational designer, an educational designer, a digital learning producer, and the manager of digital learning design. Later a video producer also joined the team.

The learning design team met weekly for a three-hour meeting over a three-week period, then for ad hoc online meetings as needed over April to July, prior to the first live run of the MOOC in August 2022. A dedicated Microsoft Teams space was created for storage and update of shared documents and communication between Deakin University and NARI team members. The series of joint team meetings involved the following activities/outcomes:

- **Team building** – learning the role of each team member, the project brief and objectives and setting up a series of meetings and communication methods.
- **Developing a course development schedule** over the four-month period before the scheduled first MOOC run.
- **Learning about the features and structure of a MOOC.** This involved gaining an understanding of the potential of the MOOC features and learning the language of FutureLearn. For example, FutureLearn courses are structured into weeks, activities and steps not, units and modules. It has educators, not instructors, and learners, not students. The content we had prepared was organised into modules, so we needed to rearrange the content in the FutureLearn format before we could progress.
- **Developing a detailed FutureLearn course proposal** which is required by FutureLearn to approve a course. We also devised a plan for images, links, downloadable handouts, and recording and editing of video content.
- **Mapping out the course content in MOOC structure.** To do this, we used, [Mural](#), a digital whiteboard which offers a shared and dynamic visual environment, where the team could collaborate in the development of the outline and sequence of the learning materials. Mural uses virtual sticky notes and text which can be moved around and edited. It was also used for communication about the work, and a repository for images and other graphic materials that were developed specifically for the MOOC. The learning materials were designed to be organised into five weeks with approximately 3 hours of learning per week. An example screenshot of a portion of the Mural screen for the course outline is shown in Figure 1.
- **Writing a detailed learning design storyboard.** When we were all satisfied that the Mural board was complete, the next stage was to transfer the MOOC structure to a detailed learning design storyboard which maps out the details of every aspect of the MOOC including the content. This is used by the educational designers to build the MOOC structure and populate the structure with the learning materials.

MOOCs are designed with accessibility features imbedded and comply with Web Content Accessibility Guidelines (WCAG) 2.1 (FutureLearn, 2023e). To meet these requirements the MOOC was designed to include downloadable summary documents and the use of simple conversational tone with simple language. PAG members emphasised the need for the use of correct medical terms, so where these are used, the terminology is explained in a glossary document which can be downloaded by the learner. In each week subheadings and separate 'pages' are used to break up the text, alternative text is available for all images, descriptive hyperlinks are used, and there are transcripts available for each of the videos. Care was taken during the writing process to make the language as inclusive as possible by trying not to make assumptions related to cultural practices about personal hygiene and toileting.

- **Developing the video content** - part of the success of MOOC's is that they are visually engaging. The project team reviewed available video content on the internet and decided that we needed to develop our own content to adequately give voice to experienced carers of people living with dementia and incontinence within the MOOC. To achieve this, members of the PAG were invited to participate in a short video interview about salient issues that drew on their personal experience of caring for a person with dementia and incontinence.

The interviews were semi structured with the main topics covering, managing night-time continence care needs and sleep disruption, factors that affect carers' experience of continence caregiving, including role changes and assisting the person with toileting and personal hygiene, caring for yourself and the role of support groups. Formal written consent was obtained and PAG members were remunerated for their time. Three of the PAG carers took part in the interview process.

Additionally, we also conducted three other interviews with health professionals who are experts in their fields. The first was focused on the basis for beliefs about incontinence and the effect of these beliefs on attitudes to adults with incontinence; the second concerned the varying roles of health professionals in a multidisciplinary continence care team; and the third focused on skin issues that can occur with incontinence and how to protect the skin. FutureLearn also includes the 'let's get started' video - a welcome and general introduction to the course which three members of the project team contributed to. Filming took place over four days either face-to-face or via zoom with the direction of the video producer. The face-to-face interviews were conducted at a simulation facility at Deakin University, designed and set up to simulate a home environment. The initial processing and initial editing of the video material was done by the video producer. Then, using Vimeo as an online editing software, members of the project team were able to edit the video content. Final editing and production were done by the video producer and then loaded into the MOOC platform by the educational design team.

- **Final editing and revision of the MOOC** – prior to run 1, PAG members and a purposively sampled group of key stakeholders were invited to review the content and provide feedback about its applicability, acceptability, and feasibility. Feedback was received via email to the project manager. This informed final revisions to the MOOC.



Figure 1. Screenshot from Mural platform illustrating course outline planning.

Table 1. Outline of the MOOC content by weeks

	WEEK 1	WEEK 2	WEEK 3
STEPS	Coping with the lived experience	The basics of bladder & bowel structure and function	Promoting healthy bladder and bowel function & assisting with toileting & hygiene
	Introduction to the course	The basics of bladder & bowel function	How to optimise healthy function
	Let's get started video	What is normal bladder and bowel structure and function?	What are good bladder and bowel habits?
	Learning online with Deakin	Normal urine and faeces	Good toilet habits
	Introduce yourself and share your story	Pelvic floor muscles	Factors that hinder continence for people living with dementia
	Week overview	Achieving continence is harder than you think	Applying good bladder and bowel habits to a person living with dementia
	Beliefs and misbeliefs about incontinence	Effects of ageing and dementia	Keeping a bladder and bowel diary
	Common beliefs about incontinence	How the bladder and bowel change with age	Toileting without trauma
	Where do beliefs about incontinence originate?	How dementia affects the bladder and bowel	Identifying when assistance is needed
	Beliefs about incontinence being an attention seeking act	Other health issues that affect the bladder and bowel	Providing toileting and hygiene assistance
	Understanding how incontinence affects emotions	Additional factors that affect bladder and bowel function	Finding words and symbols to describe the toilet and bathroom
	Understanding how incontinence affects behaviours	Warning signs – when to follow up with a health professional	Establishing a toileting and hygiene program
	Understanding factors that can affect carers experience of continence caregiving	Weekly wrap	Managing night-time continence care needs
	Communicating for success	Key ideas and principles – week 2	Toileting related behaviours that can be challenging
	Why communication skills are important in continence caregiving	What's on for next week	Creating a physical environment that supports continence
	Key strategies to minimise distress and conflict when supporting a person with their continence care	Check your understanding - Quiz	Weekly wrap
	Weekly wrap		Key ideas and principles – week 3
	Key ideas and principles – week 1		What's on for next week
	What's on for next week		Check your understanding - Quiz

	WEEK 4	WEEK 5
STEPS	Using continence aids & incontinence products	Coping at home, out and about & accessing quality information
	Assisting with the use of continence aids & incontinence products	Coping at home & out and about
	Continence aids to optimise continence	Planning, problem solving and flexibility in managing continence care needs
	Incontinence products to manage incontinence	Knowing the person
	Choosing the right incontinence product	Planning and problem solving
	What can go wrong with incontinence products?	Tips for getting out and about or travelling
	Disposal of single-use incontinence products	Dealing with accidents when out and about
	Minimising odour	Advocating for the person and their needs
	Assisting people living with dementia to use continence aids and incontinence products	Strategies for working in partnership with the health care team
	Funding schemes and purchasing products	Accessing quality information and support
	Protecting the skin	Finding reliable health information online
	Protecting the skin	Accessing help from a continence service
	Weekly wrap	Roles of the multidisciplinary team in continence care
	Key ideas and principles – week 4	Caring for yourself
	What's on for next week	Role of support groups
	Check your understanding - Quiz	Course wrap
		Key ideas and principles – putting it all together
		Assess your knowledge – final course quiz
		Further learning with NARI and Deakin

Implementation

The plan was to conduct two runs in 2022 and one in 2023. A 'run' in FutureLearn is one "edition" of a course, which starts and ends on specific dates. Learners can enrol at any time from the time it is published (goes live) until the end of the extended enrolment window. The Caregiving, Dementia and Continence MOOC has been designed over a 5-week period. When learners sign up, their access begins, and they have a nine-week period to complete the MOOC free of charge.

Normally a MOOC will run for at least a one-year period. During a run, only minor changes can be made to the content and no structural changes can be made to the MOOC. Therefore, the project team made the decision to have the first two runs over a six-month period so we could make changes as needed and be responsive to feedback from learners, their engagement in discussion/comments, and their use of learning materials. We can monitor student engagement within the moderator view/login in the FutureLearn platform. The runs were scheduled as follows:

Run 1 – 1 August – 30 September 2022

Run 2 – 17 October – 23 December 2022

Run 3 – 30 January 2023 – current.

4.5 Phase 3: Dissemination, facilitation, and maintenance (Months 15-24)

Phase three involved ensuring the MOOC was promoted widely to reach the target groups, facilitating, monitoring, and maintaining it to ensure it was fit-for-purpose. Revisions were scheduled between runs based on data analytics and learner feedback. Data analytics from FutureLearn provided real time information about the number of people enrolled and publicly posted learner reviews.

Dissemination

The project team developed a promotional plan which included contacting relevant local, national, and professional special interest groups. Several key international organisations were also targeted. Additionally, we developed a social media plan, digital flyers with more detailed information about the MOOC and several press releases. In developing our media plan, we sought advice from the Chief investigators group, the PAG, NARI staff experience in media, and the NARI media advisors.

Starting prior to the first run in August 2022, we targeted the following groups via social media (Facebook, Twitter, LinkedIn) every two weeks for two months:

- Individuals living with dementia.
- Formal and informal carers of people living with dementia.
- Individuals and organisations that advocate for the needs of people living with dementia and their carers.
- Individuals and organisations that advocate for the needs of people with continence care needs, and their carers.

We also emailed approximately 60 peak professional, educational, health, and government organisations with media information they could use in their own organisations and links to the MOOC related social media. The first email was just after the first run commenced in August 2022 and the second at the start of the 3rd run in February 2023.

The response from many organisations was excellent, with several organisations adding the information to their website, blogs, news items, and member newsletters. Some education organisations which were not directly contacted also picked up the information via social media. Appendix 4 includes a list of organisations that promoted the MOOC.

Facilitation

Facilitation within a MOOC involves educators engaging with learners in the comment section within the 'steps' each week. This process of replying to learners' comments, answering their questions, and pinning strong comments to the top of conversation threads, assists learners to learn vicariously (FutureLearn, 2023). The comments from learners also assist the facilitator to identify how learners are interpreting content and the questions that arise can direct future revisions.

By adopting a conversational and supportive tone in comments and discussions, educators build rapport, establish a climate for learning and a supportive learning environment, encourage learners to engage with each other, and suggest additional learning resources when needed. All the comments remain within the MOOC so learners in the future can read previous interactions. Learners can choose to use their full name or a pseudonym in their learner profile.

The MOOC is written in English and most learners write their comments and discussions in English. However, we experienced two occasions when learners wrote in languages other than English: one in Spanish and the other in Polish. The facilitator was able to use Google translate to work out what the person was writing and then was able to reply in English. Additionally, most of the resources and weblinks are Australian. One of the heartening aspects of facilitation of the MOOC has been observing the learners from around the world share links to their local resources with other learners as well as their own learnings from their caregiving experiences.

Not all FutureLearn short courses are actively facilitated. However, given the sensitive nature of the content of the MOOC and the potential vulnerability of the learners, the project team made the commitment to provide facilitation on weekdays. This was especially important in the first run when we needed to be very responsive to any difficulties learners were having. The time taken for facilitation varies from day to day depending on the number of new learners and the amount of discussion taking place. On average the facilitation takes approximately 15 minutes per day. Occasionally when the discussion activity has reduced, the educator can add in questions or highlight a specific topic to encourage learner engagement.

Revision

As noted previously, only minor revisions to the MOOC content and structure can be made during each 'run' when learners are active. During each run the educator kept detailed notes about any changes that needed to be made. For example, editing or revision of embedded links to external websites, changes of the name of organisations, the need to update reference material, etc. We also paid particular attention to the questions from the learners and reviewed the related content for clarity and detail. Any changes can then be communicated (week by week – detailed for each step) to the Deakin Global Studios learning design team via a shared update document on Microsoft Teams.

Revisions for run 2:

- Edits to the text to improve the clarity of the writing.
- Changes to some of the text in the learning activities (tasks) to be more inviting of learner comment and engagement.
- Added additional resources as they were discovered. For example, dementia specific resources for Aboriginal and Torres Strait Islander peoples and resources for carers of LGBTI people who are living with dementia. Incorporated links to continence resources in languages other than English.

- To address learner's questions that were appearing in the discussions, we wrote additional content on the structure and function of the bowel and the kidneys, types of incontinence, and further information about skin care products that are designed to prevent skin breakdown in people with incontinence. Once we made these changes prior to run 3, there have been no further questions from learners related to this content.

Revisions for run 3:

- Removed the steps related to the research survey questionnaires as the time-period for data collection was completed.
- Further edits to text to improve the clarity of the writing.
- Added in further resources about male carers in response to the increasing number of male carers enrolled in the MOOC.

5. EVALUATION

The evaluation consisted of an anonymous online survey that was built into the MOOC. Research participants were invited to complete the online survey prior to engaging with (T1) and at the completion (T2) of the MOOC content. The primary outcomes of interest were:

- Relevance and usability of the MOOC content by carers
- Carer burden and associated quality of life (QoL).

We anticipated engagement with the MOOC by carers would provide them with information and resources that were applicable to their everyday caring responsibilities, which would translate to reported carer burden and QoL. For the first outcome, the T2 online survey additionally included seven questions asking the research participants to rank the MOOC contents useability and applicability. They were additionally invited to provide written feedback. For the second outcome, the research participants were invited to complete measures addressing carer burden and QoL at T1 and T2.

Information about the opportunity to participate in the evaluation was placed at the beginning and at the end of the MOOC. The research participants were informed that their participation in the project evaluation was entirely voluntary and would not affect their ability to complete the MOOC or receive certification in any way. No other data provided by the research participants during the MOOC was monitored or analysed for research. At the end of the online survey, there was an opportunity for research participants to self-select to be interviewed about the extent to which the MOOC reduced distress and conflicts related to caring for a person with dementia and incontinence. The interviews were to be digitally recorded and transcribed verbatim by the research team. Twenty interviews were planned.

5.1 Data Collection

Online surveys

Research participants were invited to complete a T1 and T2 anonymous online survey. The T1 survey collected minimal demographic information, which included a participant identification number, age, gender, country of residence, carer type, and length of time as a carer. The research participants were also invited to complete four QoL measures at T1 and T2: ICIQ-Cog-P (comprising eight items) (see Appendix 5), ICIQ-Cog-C (comprising four items) (see Appendix 6), EQ-5D-3L (comprising five dimensions of health and a Visual Analogue Scale - EQ-VAS-Total Health Today [THT])(see Appendix 7), and the ZBI-12 (comprising 12 items) (Appendix 8). The T2 online survey additionally invited research participants to give feedback and to comment

on their experience of the MOOC. The feedback comprised seven Likert-scale response questions (Appendix 9), and two open-ended questions.

Online QoL survey measures

The ICIQ-Cog (*International Consultation on Incontinence Questionnaire Cognitively Impaired Elderly*) is a measure designed to gather information on; (i) incontinence-related bother (ICIQ-Cog-P) and (ii) level of care efforts associated with caring for the person living with dementia (ICIQ-Cog-C) (Volz-Sidiropoulou et al., 2018). The two ICIQ-Cog scales provide observable behavioural indicators of symptoms in the person living with dementia and incontinence (ICIQ-Cog-P), and indications of the level of burden on the caregiver (ICIQ-Cog-C) (Volz-Sidiropoulou et al., 2018). The scales can be administered together or separately depending on their purpose (Volz-Sidiropoulou et al., 2018) (Appendices 5 & 6).

The ICIQ-Cog-P comprises a 12-item Likert-scale scoring ranging from 1 (*'seldom' [1-2 times a week in the last two weeks]*) to 4 (*'very often' [several times a day/every day in the last two weeks]*). Higher scoring indicates higher levels of incontinence-related bother experienced by the person with dementia. (*For the purposes of this Project, the number of items were reduced from 12 to eight because several items were not identified as necessary to the Project's focus and intent. Six of the original 12 statements were revised to be relevant to the MOOC research participants. Permission was sought and given from the scale authors to rewrite and reduce the number of items from 12 to eight). Each item on the ICIQ-Cog-P measure begins with the stem, *"How often in the last 2 weeks ..."*. The ICIQ-Cog-C comprises four items with a Likert-scale scoring ranging from 1 (*strongly disagree*) to 4 (*strongly agree*). Higher scoring indicates a higher caregiver burden. The maximum scoring for the ICIQ-Cog-P and ICIQ-Cog-C are 32 and 16 respectively (Volz-Sidiropoulou et al., 2018). Internal consistency (Cronbach's alpha (α)) of 0.69 - 0.82 are reported along with test-retest reliability of 0.71 - 0.82 (Volz-Sidiropoulou et al., 2018). The measures have been validated in other settings with correlation coefficients (strength of linear relationships between the two variables) of 0.69 (ICIQ-Cog-P) and 0.62 (ICIQ-Cog-C) additionally reported (Jaekel et al, 2023).

The EQ-5D-3L is a generic, non-disease-specific measure of health status developed by an international research group, the Euro Quality of Life group, established in 1987 (Rubin & de Charro, 2001). The EQ-5L-3L comprises two components: a five-dimension descriptive system that measures impairments in aspects of health and the EQ-VAS-Total Health Today [THT] a visual analogue scale (Appendix 7). The five dimensions in the descriptive system are mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (Teni et al. 2023). Each of the five dimension of health includes a three-answer options (levels) to measure whether respondents are experiencing 1 (*'no problems'*), 2 (*'some or moderate problems'*), or 3 (*'severe / extreme problems'*) (Teni et al., 2023). Total scores range from five to a maximum score of 15. Higher scores indicate an increased level of health impairment. The EQ-VAS-THT component contains a scaled vertical line ranging from zero (0) (*'the worst health you can imagine'*) to 100 (*'the best health you can imagine'*) where respondents rate their overall health status (Teni et al., 2023). The EQ-5D-3L demonstrates validity and responsiveness (Bhaduri et al., 2020).

The ZBI-12 [*Zarit Burden Interview*] is a shorter version of the extensively and globally used ZBI-22 (Zarit et al., 1985). The ZBI-22 is the measure most consistently used in dementia caregiving research (Bédard et al., 2001, Chiao et al., 2015). The two-factor ZBI-12 was proposed and developed by Hébert and colleagues (2000) and is considered a fast, valid, and efficient option for screening the phenomenon of carer burden (Gratão et al., 2019). The ZBI-12 comprises 12 items with Likert-scale option responses (Appendix 8). Each item is scored from 0 (*'never'*) to 4 (*'nearly always'*). Total scores range from 0 to a maximum score of 48. For the ZBI-12, a total score of between 0-10 is a *'no to mild burden'*, a total score of 10-20 a *'mild to moderate burden'*, with a score >20 is considered a *'high burden'* (Hébert et al., 2000). The ZBI-12 has demonstrated very good internal consistency ($\alpha = 0.81$ to $\alpha = 0.88$) (Bédard et al., 2001, Gratão et al., 2019). Correlations between the short-

version ZBI-12 and the full version ZBI-22 ranged from 0.92 - 0.97, with two-way analysis of variance producing identical results between the two measures (Bédard, et al., 2001). In this Project, professional carers and those with no experience of caring were prompted to not complete the ZBI-12.

Sample size estimation and justification

The online survey: The T1 and T2 online surveys were targeted to learners engaging with the MOOC. However, it was difficult to predict what the size of this target population would be. A sample size estimate was based on FutureLearn's experience running a similar MOOC, with approximately 3000 participants per course. We calculated a minimum sample size of 341 survey responders, with a confidence level of 95% and a 5% margin of error, to produce reliable results in a highly representative sample.

5.2 Data Analysis

Quantitative analysis: Data analyses were performed using the SPSS Statistics for Windows, Version 28.0. The quantitative data collected were described using means and standard deviations for normally distributed continuous data, and numbers and percentages for categorical data. The non-parametric Wilcoxon Signed Rank Test were performed on the completed and paired T1 and T2 QoL measures.

Quantitative analysis: The qualitative data collected from the MOOC research participants were examined for recurring themes.

6. FINDINGS

6.1 Findings from the Project Advisory Group

The PAG consisted of three community-dwelling people with a MMSE > 18 and self-reported mild dementia and incontinence; (ii) eight family carers who supported them to manage incontinence or maintain continence; and (iii) eleven nursing home employees with experience of assessing or providing continence care to people with dementia, most of whom also had personal experience of caring for a family member living with dementia. Discussions with the PAG yielded several recommendations about caring for a person with dementia and incontinence. They included:

- Know the person and ensure you have their trust
- Be flexible and anticipate changes in the person's abilities/behaviours
- Develop strategies to reduce frustration and anxiety for both
- Anticipate and manage embarrassment of both
- Know how and when to access appropriate professional help
- Develop practical skills and information to manage 'accidents' in social situations
- Know what to expect – i.e., what is normal function of bowel and bladder and how dementia impacts
- Anticipate having to 'problem solve' challenges the person may experience
- Develop strategies to minimise incontinence, particularly at night
- Ensure a diet that optimises bowel regularity
- Learn to advocate for the person in encounters with the healthcare system to ensure alignment

between the goals/needs of the person, carer and healthcare professionals

- Anticipate the possible negative effects of changes such as changes in medication, surgery or respite care on the person's continence and bowel and bladder function/control
- Know how to access and use continence aids and incontinence products
- Anticipate having to manage your own and the other person's emotions
- Be aware of the effect of constant watchfulness on your own health

These recommendations were synthesised with findings from a scoping review on dementia and incontinence, and resulted in the following five overarching topics:

1. Coping with the lived experience
2. Basics of bowel and bladder function
3. Promoting healthy bowel and bladder function and assisting with toileting and hygiene
4. Using continence aids and incontinence products and protecting the skin
5. Coping at home, out and about and accessing information and support

These five overarching topics are reflected in the way that the course was designed (Table 1).

6.2 Findings from FutureLearn's evaluation of the MOOC

As of June 30, 2100, learners have enrolled in the MOOC since the first run in August 2022. The educational design team from Deakin Global Studios extracted user data from the Future Learn platform for each run. The following provides context to performance data of the course to the performance of 44 other available Deakin Free Open Courses on FutureLearn in the period 14 Jun 2022 – 13 Jul 2023 inclusive

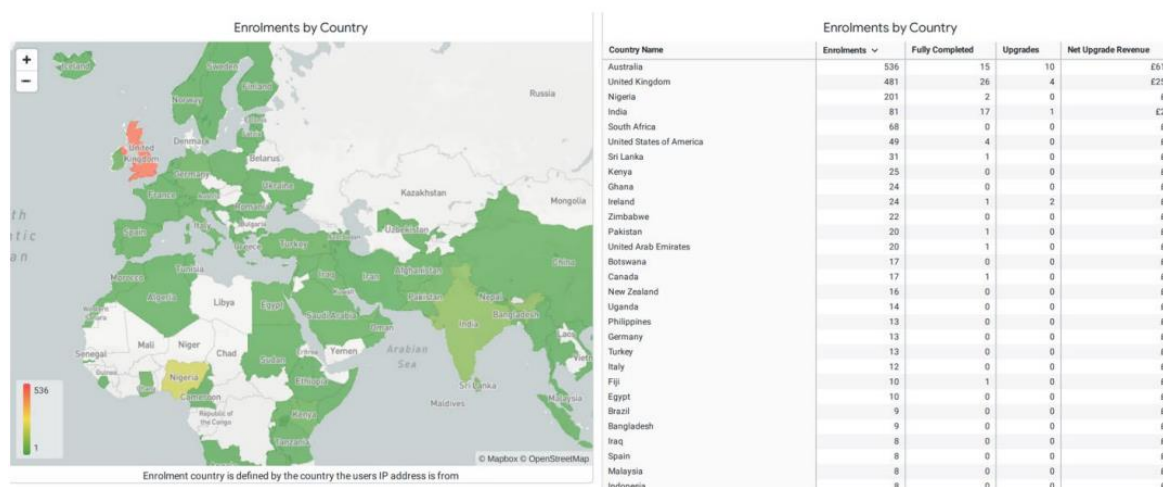
- Third best performing course for total enrolments.
 - 7.1% of overall enrolments.
- Fourth best performing course for average enrolments (based on per course run)
 - Average of 714 enrolments per run.
- Fourth best performing course for the total number of upgrades.
 - 6.8% of all upgrades.
 - Number of upgrades decreased from run 1 through to run 3.
- Seventh best performing course for the total number of completions.
 - 6.0% of all completions.
 - Completion rate increases from run 1 through to run 3.
- In run 3 – February 2023 – current:
 - 50.3% were active learners – completing steps and marking off their progress with the system.
 - 23.0% were social learners – posting at least one comment in every step. This is a high rate of learner engagement.

Enrolments by country

Learners have enrolled from 69 countries over the three runs of the course. Of the learners who completed the demographic information, the top four country of origin are:

- Australia n=536
- United Kingdom =481
- Nigeria n=201
- India n=81

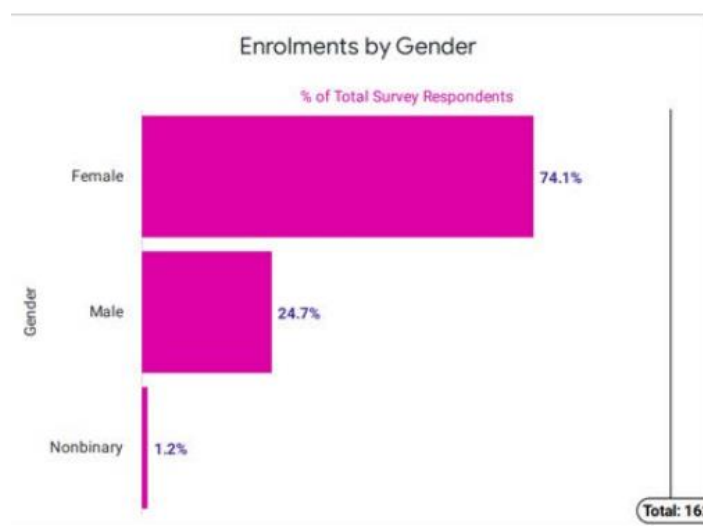
Table 2. Enrolments by country



Learner characteristics

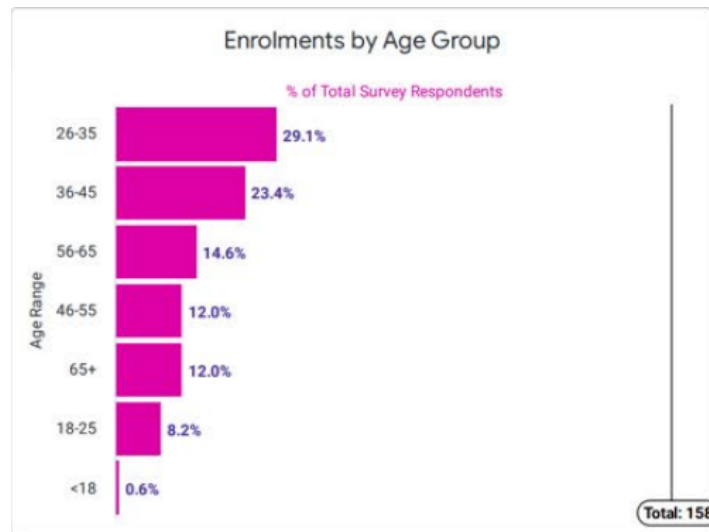
Some of the data is captured when the learner enrolls, however as the information is not compulsory, there are significant gaps in information about learners' characteristics i.e. the data does not represent the entire learner profile. Of the learners who provided information about their gender (n=162), 74.1% identified as female, 24.7% as male and 1.2 as nonbinary (see Table 3).

Table 3. Enrolments by gender



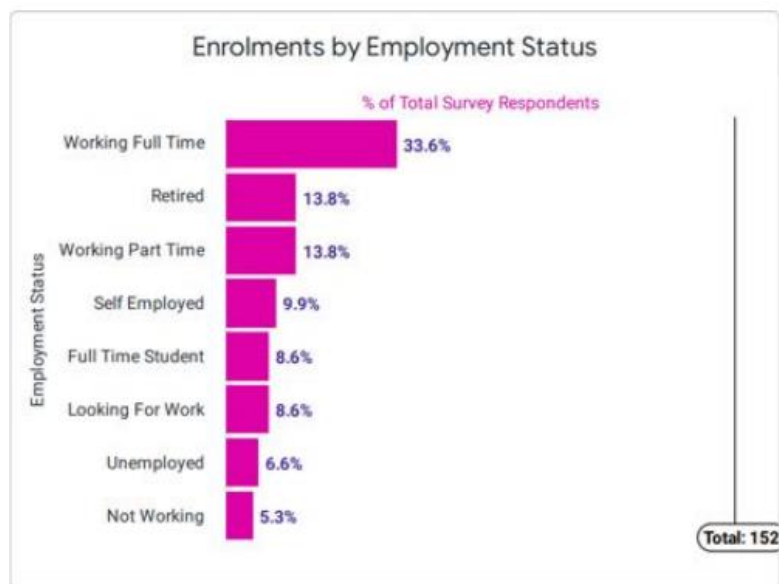
Of the 158 learners who provided information about their age, 29.1% were aged between 26-35 years of age and 23.4% were aged between 36-45% (see Table 4).

Table 4. Enrolments by Age Group



Of the 152 learners who provided information about their employment status, the majority (33.6%) reported working full time, with 13.8% indicating they were retired and 13.8% working part-time (see Table 5).

Table 5. Enrolments by Employment status



Satisfaction with the MOOC

Learner feedback about each week's content for each run was sought by asking participants to click on the face that best represented their satisfaction (see Table 6).

Table 6. Learners' satisfaction with the course

Weekly sentiment survey:

			
Week 1	Run 1: 100%	Run 1: 0%	Run 1: 0%
	Run 2: 89%	Run 2: 0%	Run 2: 11%
	Run 3: 100%	Run 3: 0%	Run 3: 0%
Week 2	Run 1: 63%	Run 1: 25%	Run 1: 13%
	Run 2: 100%	Run 2: 0%	Run 2: 0%
	Run 3: 100%	Run 3: 0%	Run 3: 0%
Week 3	Run 1: 100%	Run 1: 0%	Run 1: 0%
	Run 2: 100%	Run 2: 0%	Run 2: 0%
	Run 3: 100%	Run 3: 0%	Run 3: 0%
Week 4	Run 1: 88%	Run 1: 0%	Run 1: 13%
	Run 2: 100%	Run 2: 0%	Run 2: 0%
	Run 3: 75%	Run 3: 0%	Run 3: 25%
Week 5	Run 1: N/A	Run 1: N/A	Run 1: N/A
	Run 2: N/A	Run 2: N/A	Run 2: N/A
	Run 3: N/A	Run 3: N/A	Run 3: N/A

In addition, for each run, learners were invited to the following questions:

- Did the course meet your expectations?
- Did you gain new knowledge or skills by taking the course?
- Since starting the course, have you applied what you learned?
- Since starting the course, have you shared what you learned with other people?
- What (if anything) would you like to learn next in this subject area?
- Is there anything else you would like to tell us?

In the third run, 22 learners responded to these questions and provided extremely positive responses as indicated below.



Since starting the course, have you applied what you learned?

Responses (22)



Since starting the course, have you shared what you learned with other people?

Responses (22)



What (if anything) would you like to learn next in this subject area?

I will like to learn about dementia

More about dementia, diabetes, cancer, arthritis. More about healthy aging.

more on continence

No thank you . Maybe in the future.

yes

What (if anything) would you like to learn next in this subject area?

I will like to learn about dementia

More about dementia, diabetes, cancer, arthritis. More about healthy aging.

more on continence

No thank you . Maybe in the future.

yes

Is there anything else you would like to tell us?

excellent course - thank you

It was a wonderful experience. Felt like i was in the classroom all along Thanks to the entire team who put this together.

No

I will practice some of this in the care home I work

No. Keep up the good work. Godspeed

no

6.3 Findings from the facilitation of the MOOC

From the point of view of the facilitator, the learners who engage in discussions and make comments on the social platform think deeply about the key concepts from the learning materials, apply it to their own situation, and suggest additional resources for other learners (like those referred to in the MOOC but country specific). Some learners also encourage other learners to engage in the discussion. We are unable to give examples of these discussions as the learners have not consented to their work being used outside of the MOOC however, of those that chose to make a [public comment or review](#), they expressed a high level of satisfaction – 4.7 out of 5.

6.4 Findings from the MOOC online surveys (T1 and T2)

The key findings from the Project are presented in the following order:

MOOC participants and completed online surveys

- i. Total number enrolled into MOOC.
- ii. Total number of completed T1 online surveys.
- iii. Total number of completed T2 online surveys.
- iv. Total number of completed and paired T2 online surveys.

Demographic characteristics

The demographic characteristics for MOOC research participants will precede demographic characteristics for the informal (family) carer (T1).

- i. Age and gender
- ii. Country of residence
- iii. Carer type (all MOOC research participants only)
- iv. Length of carer experience

MOOC content feedback

- i. Online survey quantitative feedback (T2)
- ii. Online survey qualitative feedback (T2)

Quality of life (QoL) measures

- i. Summative scores (*M*, *SD*) for QoL measures (*ICIQ-Cog-P*, *ICIQ-Cog-C*, *EQ-5D-3L*, *EQ-VAS-THT*, *ZBI-12*) for 1] all MOOC research participants and, 2] for the informal (family) carer group (T1).
- ii. Summative scores (*M*, *SD*) for ICIQ-Cog measures for the carer groups: **Group 1** (informal family carer), **Group 2** (aged care employee), **Group 3** (home care employees), **Group 4** (other) (T1).
- iii. Quality of life measures paired test analyses (T1 and T2).

6.4.1 MOOC participants and completed online surveys

At the designated survey cut-off time (3/4/2023), 1909 learners had enrolled into the MOOC. Of these, 81 (4%) completed the T1 online survey. Seventy-five (75) non-duplicate online surveys were completed by the MOOC research participants at T1, with 21 non-duplicate surveys completed at T2. There were seven (7) completed and paired online surveys at T2.

Demographic characteristics (MOOC participants - T1)

Table 7. Age and gender

	<i>n</i>	Range	<i>M</i>	<i>SD</i>
Age		16-81 years	45.25	15.59
Gender				
Male	12 (16%)			
Female	62 (82.6%)			
Gender Fluid	1 (1.4%)			
TOTAL	75			

Of the 75 MOOC research participants who completed the T1 online survey, one identified as being gender fluid, 12 as male, and 62 as female. The age range was between 16 years and 81 years, with a mean age of 45.2 years. The standard deviation score, relative to the mean, indicates a clustering of scores around the mean score.

Table 8. Country of residence

Residence		
Country	Freq	%
Australia	25	33.3
Barbados	1	1.3
Bangladesh	2	2.7
Botswana	1	1.3
Canada	2	2.7
Dom Rep	1	1.3
Fiji	1	1.3
Ghana	2	2.7
Greece	1	1.3
India	1	1.3
Indonesia	1	1.2
Kenya	2	2.7
Nigeria	4	5.3
Pakistan	2	2.7
S. Africa	3	4
Slovenia	1	1.3
UK	20	26.7
USA	2	2.7
Vietnam	1	1.3
Missing	2	2.7
TOTAL	75	100

Research participants from a total of 19 countries of residence completed the T1 online survey. Country of residence included the Oceania region, Northern Europe, Asia, African continent, North America, Southern Europe, Eastern Europe, and the Mediterranean. The largest number of residents from individual countries included Australia with 25 followed by the United Kingdom with 20. Four (4) research participants were from Nigeria, and three (3) from South Africa. Research participant numbers from other countries ranged from one to two.

Table 9. Carer type

Scoring	Freq	%
1. Informal (family) carer	30	40.00
2. Aged care employee	11	14.70
3. Home care employee	12	16.00
4. Other	10	13.30
5. I have never been a carer	9	12.00
6. Was a carer but no longer	2	2.70
Missing	1	1.30
TOTAL	75	100.00

Informal (family) carers were the largest number of MOOC research participants, with 30 completing the T1 online survey. Twelve identified as home care employees followed by 11 as aged-care employees. The 'other' research participants who provided their professional status included a diversity of healthcare professionals including clinical psychologist, disability support worker, pharmacist, case manager, aged-care advocate, intensive care physician, EN's, and RNs. Nine identified as never being a carer.

Table 10. Length of carer experience

Scoring	Freq	%	M	SD
1. Less than 1 year	17	22.70		
2. 1-5 years	18	24.00		
3. 6-10 years	7	9.30		
4. 11-15 years	2	2.70		
5. 16-20 years	6	8.00		
6. Greater than 21 years	8	10.70		
7. I am not a carer	15	20.00		
Missing	2	2.70		
TOTAL	75	100.00	3.36	2.34

The length of carer experience ranged from less than one year to greater than 21 years. A total of 35 research participants had been carers for up to five years. Seven (7) identified as having been carers for between six and 10 years, eight between 10 and 20 years, and eight (8) more than 21 years. Fifteen research participants reported as not being a carer.

Demographic characteristics (informal [family] carer - T1)

Table 11. Age and gender

	<i>n</i>	Range	<i>M</i>	<i>SD</i>
Age		21 to 80 years	45.54	16.27
Gender				
Male	6 (20%)			
Female	24 (80%)			
TOTAL	30			

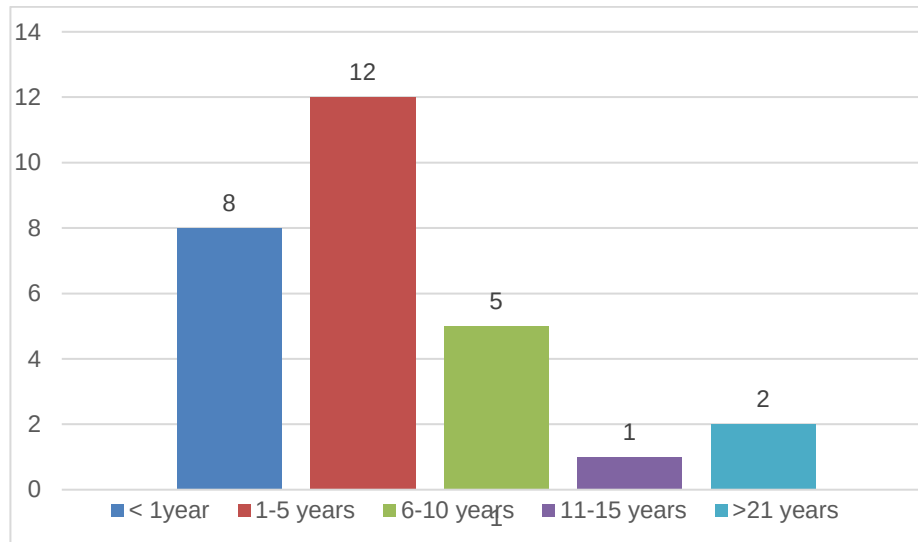
Within the informal (family) caregiver group, six (6) research participants identified as male and 24 as female. The age range was from 21 years to 80 years of age, with the mean age of 45.5 years. The standard deviation score, relative to the mean, indicates a clustering of scores around the mean score.

Table 12. Country of residence

Country	Freq	%
Australia	5	16.7
Bangladesh	1	3.3
Canada	1	3.3
Fiji	1	3.3
Ghana	2	6.7
Greece	1	3.3
Indonesia	1	3.3
Kenya	1	3.3
Nigeria	4	13.3
Pakistan	2	6.7
S. Africa	1	3.3
Slovenia	1	3.3
UK	6	20.0
USA	2	6.7
Vietnam	1	3.3
TOTAL	30	100

Among the informal (family) carer group, residents from 15 countries completed the T1 online survey. Country of residence included the Oceania region, Northern Europe, Asia, African continent, North America, Southern Europe, and the Mediterranean. The largest number of residents from individual countries were from United Kingdom with six (6), followed by Australia with five (5), and Nigeria with four (4).

Table 13. Length of carer experience

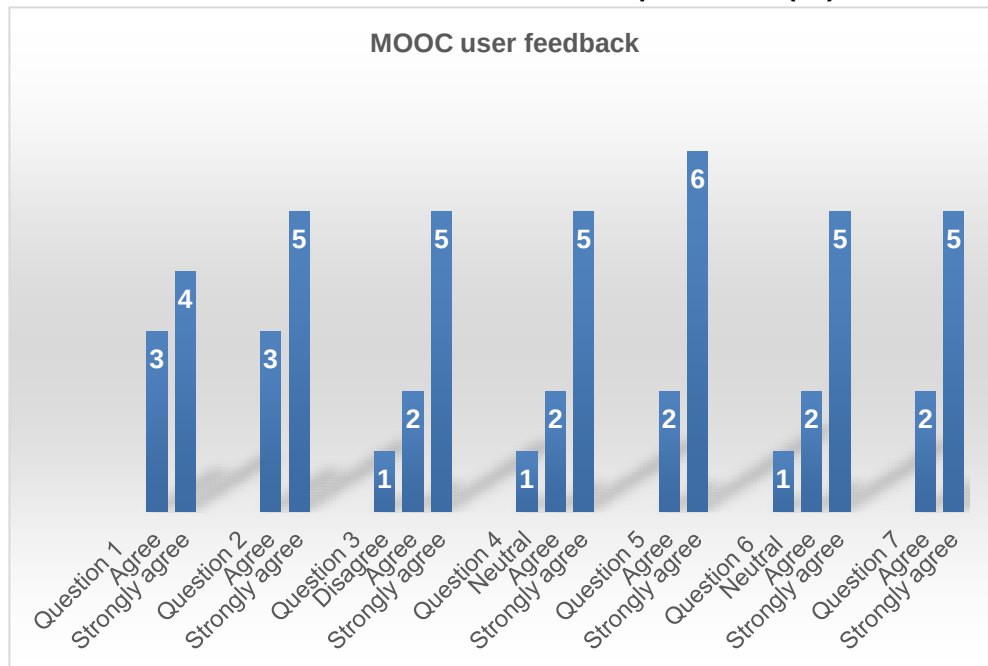


Among the informal (family) carer group who reported their length of time as a carer, most had been carers for less than 10 years (25 carers). The greatest length of time as a carer was from one to five years (12 carers), followed by less than one-year (eight (8) carers) and 6-10 years (five (5) carers) respectively. Two reported being carers for over 21 years.

6.4.2 MOOC content feedback T2

Quantitative feedback

Table 14. MOOC content feedback - quantitative (T2)



At T2, MOOC research participants were invited to score seven Likert-scale questions related to the MOOC content using a 5-item option response. Eight learners completed the online questionnaire. Overall, most of the scoring for each question were rated as ‘agree’ and ‘strongly agree’. Question 5, ‘The information is applicable to my everyday life’, scored the highest for the ‘strongly agree’ response. Question 3, ‘The course was visually engaging’, was the only question that scored a ‘disagree’ by one participant.

Qualitative feedback

The MOOC research participants were additionally invited at T2 to provide responses to two open questions: 1. ‘Best things about the course’ and, 2. ‘Any other comments’. Ten research participants provided feedback to the open-response questions. The feedback was collated and examined by the project team for emerging themes. Three key themes were identified:

Theme 1

Knowledge acquisition and upskilling – illustrative examples from research participants included: lists of resources, understanding dementia and incontinence, the need for information, and an appetite for learning.

“The information provided was excellent, as well as the comments from current carers, and cameos from selected carers & highly skilled professionals”.

“I learnt a great deal and am so pleased I signed up for this course”.

Theme 2

Ease of learning -- illustrative examples from research participants included: self-paced, content layout, navigation, signposting of content, clear explanations, accessibility, and availability of MOOC.

“Easy to navigate”.

“Very logically ordered, and clearly written”.

“That it was self-paced and online”.

Theme 3

Relatable to lived experiences - illustrative examples from research participants included: videos with the carers insights, sharing with others, openness in the way topics were addressed.

“helped me to understand what is happening to my mum”.

“This course was very timely, informative and helpful for me as I try to navigate life as a carer, and they change in a life-long partner with dementia and incontinence”.

6.4.3 Quality of Life measures

Summative scores for QoL measures - all MOOC participants (T1)

Using SPSS Statistics for Windows, Version 28.0, the summative mean score and standard deviation score (*SD*) for each of the QoL measures for all MOOC research participants who completed the online survey at T1 were obtained. The results for each QoL measure are presented below.

For the *ICIQ-Cog-P*, the reported total mean score for 58 research participants (77% of the survey population) who responded to the eight (8) items was 19.75. Based on the total possible score of 32 for this scale (higher score = higher levels of incontinence-related bother), this indicates a scoring of 2 = ‘sometimes’ (on 5 - 7 days in the past 2 weeks). The *SD* score of 5.29 indicates a clustering of scores around the mean score.

For the *ICIQ-Cog-C*, the reported total mean score for 65 research participants (87% of the survey population) who responded to the four (4) items was 11.25. Based on the total possible score of 16 for this scale (higher score = higher level of care efforts and burden on the caregiver), this indicates a scoring of 3 = ‘moderately agree’. The *SD* score of 2.19, indicates a clustering of scores around the mean score.

For the *EQ-5D-3L*, the reported total mean score for 65 research participants (87% of the survey population) who responded to the five (5) issues was 6.20. Based on the total possible score of 15 for this measure (higher score = worse situation), this indicates a total scoring of between 1 and 2 for each issue (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). Based on the three-answer options (levels), these

scores were between 1 ('no problems') and 2 ('some or moderate problems'). The SD score of 1.62 indicates a clustering of scores around the mean score.

For the *EQ-VAS-THT*, the reported mean score for 63 research participants (84% of the survey population) was 75.4. Based on the scoring options of 0 to 100, with a higher score representing a higher perception of health, the scoring indicates a positive perception of health. The SD score of 22.38, indicates a clustering of scores around the mean score.

For the *ZBI-12*, the reported total mean score for 36 research participants (48% of the survey population) who responded to the 12 items was 28.94. Based on the total possible score of 48 (higher score = increased carer burden), the scoring guidelines provided by the scale authors identify that a score >20 indicates a perceived high carer burden. The SD score of 9.90, indicates a clustering of scores around the mean score. (In this Project, professional carers and those with no experience of caring were prompted to not complete the *ZBI-12*).

Summative scores for QoL measures - informal (family) carer (T1)

Using SPSS Statistics for Windows, Version 28.0, the summative mean score and standard deviation (SD) score for each of the QoL measures for the informal (family) carers who completed the online survey at T1 were obtained. The results for each QoL measure are presented below.

For the *ICIQ-Cog-P*, the reported total mean score for the 29 informal (family) carers (97% of the survey population), who responded to the eight items was 18.45. Based on the total possible score of 32 for this measure (higher score = higher levels of incontinence-related bother), this indicates a scoring of 2 = 'sometimes' (on 5 - 7 days in the past 2 weeks). The SD score of 5.97, indicates a clustering around the mean.

For the *ICIQ-Cog-C*, the reported total mean score for the 29 informal (family) carers (97% of the survey population) who responded to the four (4) items was 11.03. Based on the total possible score of 16 for this measure (higher score = higher level of care efforts), this indicates a scoring of 3 = 'moderately agree'. The SD score of 2.38, indicates a clustering around the mean.

For the *EQ-5D-3L*, the reported total mean score for the 26 informal (family) carers (87% of the survey population) who responded to the five (5) issues was 6.19. Based on the total possible score of 15 for this measure (higher score = worse situation), this indicates a total scoring of between 1 and 2 for each issue (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). Based on the three-answer options (levels), these scores were between 1 ('no problems') and 2 ('some or moderate problems'). The SD score of 1.83 indicates a clustering around the mean.

For the *EQ-VAS-THT*, the reported mean score for 25 informal (family) carers (83% of the survey population) was 77.52. Based on the scoring options of a higher score representing a higher perception of health, with a total score of 100 (higher score = better perception of health), the reported mean score indicates a positive perception of health. The SD score of 23.59 indicates a clustering around the mean.

For the *ZBI-12*, the reported total mean score for 25 informal (family) carers (83% of the survey population), who responded to the 12 items was 28.88. Based on the total possible score of 48 (higher score = increased carer burden), the scoring guidelines provided by the scale authors identifies that a score >20 indicates a perceived high carer burden. The SD score of 10.27, indicates a clustering of scores around the mean score.

Table 15. Carer groups QoL summative scores (ICIQ-Cog measures) - T1

GROUP 1 (Informal Family Carer)				GROUP 2 (Aged Care Employee)				GROUP 3 (Home Care Employee)				GROUP 4 (Other)			
ICIQ - Cog - P				ICIQ - Cog - P				ICIQ - Cog - P				ICIQ - Cog - P			
Question	<i>M</i>	<i>SD</i>	<i>n</i>	Question	<i>M</i>	<i>SD</i>	<i>n</i>	Question	<i>M</i>	<i>SD</i>	<i>n</i>	Question	<i>M</i>	<i>SD</i>	<i>n</i>
1	2.21	1.17	29	1	2.82	0.87	11	1	2.22	0.83	9	1	2.10	0.94	10
2	2.19	1.00	29	2	2.73	0.78	11	2	2.78	1.09	9	2	2.20	0.91	10
3	2.34	1.11	29	3	2.91	0.83	11	3	2.44	0.52	9	3	2.20	0.91	10
4	2.00	1.01	29	4	2.91	0.83	11	4	2.56	1.23	9	4	2.10	0.73	10
5	2.57	0.95	29	5	2.73	0.78	11	5	2.67	1.00	9	5	2.10	0.73	10
6	2.68	1.05	29	6	2.55	0.82	11	6	3.00	1.00	9	6	2.70	1.05	10
7	2.33	0.87	29	7	2.70	1.05	10	7	2.44	0.72	9	7	2.22	0.66	9
8	2.41	1.01	29	8	2.91	0.83	11	8	2.78	0.83	9	8	2.50	0.52	10
ICIQ - Cog - C				ICIQ - Cog - C				ICIQ - Cog - C				ICIQ - Cog - C			
Question	<i>M</i>	<i>SD</i>	<i>n</i>	Question	<i>M</i>	<i>SD</i>	<i>n</i>	Question	<i>M</i>	<i>SD</i>	<i>n</i>	Question	<i>M</i>	<i>SD</i>	<i>n</i>
1	3.07	0.99	29	1	3.36	0.67	11	1	3.56	0.72	9	1	2.80	0.91	10
2	3.00	0.92	29	2	3.00	0.89	11	2	2.89	0.78	9	2	2.70	0.82	10
3	3.59	0.78	29	3	3.27	0.64	11	3	3.56	0.52	9	3	3.60	0.69	10
4	1.38	0.67	29	4	1.27	0.46	11	4	1.56	0.72	9	4	1.90	0.87	10

Carer groups QoL summative scores for ICIQ-Cog measures (T1)

The two *ICIQ-Cog* measures (*ICIQ-Cog-P* and *ICIQ-Cog-C*) target carers of people living with dementia and incontinence. The eight items in the *ICIQ-Cog-P* asks carers to evaluate QoL issues associated with incontinence-related bother for the person living with dementia (the observable behavioural indicators of symptoms). The four items in the *ICIQ-Cog-C* focus on level of care efforts (level of burden on the care giver).

For the *ICIQ-Cog-P* measure, there were minimal total mean scoring differences between responses among the four (4) groups (informal (family) carer, aged care employee, home care employees, and other health care professionals) for the eight items. The mean scores for each of the eight items for each group were skewed in the ranges of 2.00 to 2.91. A score of 2 is a '*sometimes*' response.

For the *ICIQ-Cog-C* measure, there was a degree of consistency in the mean scores reported by all the participant groups for items 1 to 3 (see Table 15 highlighted areas):

1. *My caregiving responsibilities are increased by the person's incontinence.*
2. *My daily routines are dictated by the person's incontinence.*
3. *People with dementia require significantly more help to manage incontinence than people without dementia.*

The mean scores for each of these three items for each carer group were skewed in the ranges of 2.78 to 3.59 with most of the scoring reported as 3.00 and above. A score of 3 is a '*moderately agree*' response.

For item 4 of the *ICIQ-Cog-C* measure, participants in all four groups consistently rated a low mean scoring for the question '*Incontinence is a taboo topic for me and I don't like talking about it*' (mean score ranged from 1.27-1.90). A score of 1 is a '*strongly disagree*' response.

Quality of life measures paired test analyses (T1 and T2)

Of the 21 non-duplicate T2 submitted online surveys, a total of seven (7) completed and paired T1 and T2 surveys were analyzed. Using SPSS Statistics for Windows, Version 28.0, a *Wilcoxon Signed Rank Test* (non-parametric paired test) were performed for each QoL measure.

ICIQ-Cog-P

A *Wilcoxon Signed Rank Test* revealed no statistically significant reduction in carers evaluation of incontinence-related bother (as experienced by the person living with dementia) following participation in the MOOC, $z = -0.52$, $p = >.05$ (0.59), with a small effect size ($r = 0.14$). The median score of the *ICIQ-Cog-P* decreased from pre-program (T1) ($Md = 24$) to post program (T2) ($Md = 22$). The results indicate a non-statistically significant with a small effect size decrease in the scoring of reported incontinence related bother by the carer between T1 and T2, suggesting that incontinence-related bother, as experienced by the person with dementia, had not meaningfully changed.

ICIQ-Cog-C

A *Wilcoxon Signed Rank Test* revealed no statistically significant reduction in carers evaluation of the level of reported care efforts following participation in the MOOC, $z = -0.68$, $p >.05$ (0.49), with a small effect size ($r = 0.18$). The median score of the *ICIQ-Cog-C* showed no reported changes in the scores from pre-program (T1) to post program (T2). The results indicate that reported level of care efforts (burden on the caregiver) neither increased nor decreased between T1 and T2, suggesting that the reported level of carer burden had not changed.

EQ-5D-3L

A *Wilcoxon Signed Rank Test* revealed no statistically significant reduction in carers evaluation of non-disease-specific health status following participation in the MOOC, $z = -0.37$, $p > .05$ (0.70), with a small effect size ($r = 0.10$). The median score of the EQ-5D-3L increased from pre-program (T1) ($Md = 6$) to post-program (T2) ($Md = 7$). The results indicate a non-statistically significant with a small effect size increase in carer-reported health issues between T1 and T2, suggesting that the carers evaluation of their health status had not meaningfully changed.

EQ-VAS-THT

A *Wilcoxon Signed Rank Test* revealed no statistically significant reduction in carers evaluation of non-disease-specific health status, emphasising total health today, following participation in the MOOC, $z = -1.09$, $p > .05$ (0.27), with a moderate effect size ($r = 0.30$). The median score of the EQ-VAS-THT increased from pre-program (T1) ($Md = 53$) to post-program (T2) ($Md = 56$). The results indicate a non-statistically significant with a moderate effect size, higher reported perception of health between T1 and T2, suggesting a minor increase in the carers overall perception of their total health today status.

ZBI-12

A *Wilcoxon Signed Rank Test* revealed no statistically significant reduction in carers evaluation of care efforts following participation in the MOOC, $z = -0.53$, $p > .05$ (0.5), with a small effect size ($r = 0.14$). The median score of the EQ-5D-3L increased from pre-program (T1) ($Md = 29$) to post-program (T2) ($Md = 32$). The results indicate a higher, non-statistically significant with a small effect size, increase in reported carer burden between T1 and T2, suggesting an overall slight increase in care efforts. It should be noted that only four of the seven T2 ZBI-12 surveys were fully completed.

7. DISCUSSION

We set out to co-design and evaluate a Massive Open Online Course (MOOC) to support carers of people living with dementia and incontinence. The primary outcomes of interest were:

1. The relevance and usability of the MOOC content by carers
2. Carer burden and associated quality of life (QoL).

We anticipated that carer engagement with the MOOC would provide them with information and resources that were applicable to their everyday caring responsibilities, which would translate to reported carer burden and QoL.

Overall, at the time of data analysis (3rd April 2023), 1909 participants had enrolled in the MOOC. Despite these high-volume numbers, a total of 81 (75 non-duplicated) and 22 (21 non-duplicated) MOOC learners completed the T1 and T2 online surveys. Seven completed and paired surveys were identified at T2. A range of factors may have impacted their ability and willingness to complete the online surveys and potentially include issues such as carers' physical and emotional capacity, time pressures, and literacy and language constraints associated with interpreting the QoL questions.

The average age of all carers was 45 years of age (Table 7). This is an age group who, in addition to family and work pressures, are caring for a family member living with dementia and incontinence. The provision of usable, readily assessable, and easy to navigate information and resources such as those provided in the MOOC offers carers with relevant information and resources to support them in this additional caring role. The written feedback provided by the carers suggest that the MOOC was both helpful and relevant to them:

"The information provided was excellent, as well as the comments from current carers, and cameos from selected carers & highly skilled professionals".

"I learnt a great deal and am so pleased I signed up for this course".

Regarding carer gender, 12 male and 62 female carers enrolled into the MOOC (Table 7). A similar bias towards female carers was reported for the informal (family) care group (females = 24 and males = 6) (Table 11). The disproportionate number of females enrolled into the MOOC highlight that the burden of caring for family members with illness and disability continues to remain in the realm of the woman (Talley et al., 2021).

Participants from a total of 69 countries of residence registered for the MOOC. Research participants from 19 countries completed the T1 survey (Table 8). A similar diversity of country of residence (15 countries) were identified for the informal (family) care group (Table 12). Country of residence ranged across several continents suggesting that a demand for easily accessible, user-friendly, relevant information and resources on principles and practices associated with caring for the person with dementia and incontinence with dignity and respect may be universal but are not widely available internationally. While the project team were mindful of the need for cultural and social inclusivity whilst writing the content for the MOOC, that was not a primary outcome of the project, and we did not plan to have cultural appropriateness evaluated. Culturally appropriate and socially inclusive resources were added into the learning materials as they have been discovered such as specific resources for Aboriginal and Torres Strait islander peoples, and for LGBTIQ+ peoples.

For the carer type, the informal (family) carer was the largest reported cohort in the T1 group with 30 participants (Table 9). This was followed by 12 home-care employees, and 11 aged-care employees. The larger cohort of the informal (family) carer group suggests that they are actively seeking information and resources to inform, guide and support them in their caring role. It is recognised that informal carers often express the need for greater support and training on managing incontinence (Davis et al., 2021; Edwards et al., 2021; Papastavrou et al., 2007). That other healthcare professionals are also seeking this type of information may indicate a potential gap in their practical and knowledge base.

This hypothesis is supported by evidence from a systematic review that concluded existing research about education programs for formal carers fail to equip them with the knowledge and skills to support continence or manage incontinence (Ostaszkievicz et al., 2020). Nor are they designed to support these professional carers to help people adjust to changes in bodily function that affect their identity, autonomy, control, and independence (Ostaszkievicz et al., 2020) which remain a priority for people right up until death (Morgan et al., 2022). These programs fail to address the interpersonal aspects of providing continence care to care-dependent people with complex care needs. Moreover, our review of tertiary and vocational education training programs designed to prepare individuals for work in health or aged or disability care shows significant gaps in educational content about preventing or managing incontinence.

For length of carer experience, which ranged from less than one year to more than 21 years, the greatest numbers of carers were in the zero to five years categories: 35 for all MOOC users (Table 10) and 20 in the informal (family) carer cohort (Table 11). Eight users identified as being carers for over 21 years, with two from the informal (family) carer group. These extended time periods can potentially place a protracted burden on carers, which may lead to physical exhaustion, burnout, and other mental health issues. These accumulating factors can further impact on the immediate and extended family, leading to an increase in overall caregiver burden, an issue which is increasingly acknowledged in internationally published literature (Kamiya et al., 2023; Lodewyk et al., 2022; Murphy et al., 2021). Offering readily assessable, user-friendly, practical, and relevant information and resources, such as those provided in the MOOC, can enable carers and their families to make informed decisions in their day-to-day caring role for the person with dementia and incontinence. Fifteen research participants identified that they had never been carers. This result may indicate that there are a group of people in society who are seeking information and guidance on managing incontinence issues as a pre-emptive preparation for their possible future role as carer for a person with dementia and incontinence. Given this, the MOOC may have a potential application in both primary and secondary health care settings.

The collated research participant responses to the seven online feedback questions, and the two open-ended questions at T2 highlight that the MOOC is addressing the participants' needs regarding supportive information on caring for the person living with dementia and incontinence. Both the quantitative and qualitative feedback highlight that the MOOC content provided the type of practical information and shared experiences that carers could use in their day-to-day caring role.

The scoring for each of the seven Likert-scale feedback questions were in the 'agree' to '*strongly agree*' categories. The highest overall scoring was associated with question 5 - *the information was applicable to my everyday life* and suggests that the MOOC content provided relevant practical information to support the carer in their day-to-day role (Table 14).

The key themes that emerged from the qualitative feedback ('*knowledge acquisition and upskilling*', '*ease of learning*' and, '*relatable to lived experience*') highlight that the MOOC not only provided relevant information and practical strategies to carers, but also provided them with an opportunity for existential growth and understanding associated with caring for a person living with dementia and incontinence, and the important role that dignity and respect play in providing care. (On a cautionary note, these responses were provided by a small number of respondents (10 in total) and may not necessarily wholly reflect the thoughts and views of the other MOOC participants.)

Nevertheless, the public facing, online, open feedback provided in the MOOC highlight the course as being valuable to carers in supporting them to care for the person living with dementia and incontinence with dignity and respect:

“The course also gives you knowledge and practical strategies to support a person living with dementia and incontinence”.

“I would recommend other people to take this course as you will learn a lot. It will help anyone who is interested/ caring for you to learn more about dementia, incontinence and help you to care for the Individual who you care for”.

“Ideal for anyone new to caring for a relative and having to deal with personal care issues”.

For the ICIQ-Cog-P scale, which measures the carers reported levels of incontinence-related bother observed in the person with dementia, the collated mean scores across all four (4) carer groups identify a predominantly ‘sometimes’ response (Table 15). This represents a score of 2 out of a possible total score of 4 for each of the 8 items. The responses indicate that the experience of incontinence did not appear to be particularly bothersome to the person with dementia.

One explanation for these responses could be that the person with dementia is yet to experience or are still in the early and manageable stages of incontinence. It may be that the MOOC research participants are using the MOOC to acquire information and practical skills about incontinence to better prepare them for what may lay ahead in their caring role. Another explanation for carers reporting an observed lower level of incontinence-related bother in the person with dementia may be that they (the person with dementia) are at an advanced stage of their disease, and it may be challenging for the carer to discern behaviours that can be attributed solely to incontinence. There appears to be a dearth of published literature that explores the lived experience of incontinence as experienced by the person with dementia. Further conversations with carers may provide some useful insights into the evolution and experiences of incontinence-related bother for the person with dementia, and for future MOOC iterations.

The two scales measuring care efforts associated with incontinence (ICIQ-Cog-C) and overall carer burden (ZBI-12) reported higher levels of caregiver burden across all four (4) caregiver groups. (NB. Those who identified as professional carers and who have not been a carer were prompted to not complete the ZBI-12 scale.) For the ICIQ-Cog-C, the mean score was mostly reported as a ‘*moderately agree*’ response. This represents a score of 3 out of a possible total score of 4 for items 1 to 3. (Item four (4) will be discussed separately.) For the ZBI-12, the overall mean score was greater than 20 indicating an elevated level of perceived carer burden (Hébert et al, 2000).

For the ICIQ-Cog-C, issues associated with increased caregiving responsibilities, increased time and effort required to care for the person with dementia and incontinence and the disruption this had on the carer’s lives contributed to the reported caregiver efforts and burden. For the ZBI-12, higher levels of caregiver burden were particularly associated with tensions between the carer having time to themselves and the feelings that they should be doing a better job of caring for the person with dementia and incontinence. Increased levels of caregiver burden - both physical and emotional - in the context of dementia have been reported in the literature (Chiao et al., 2015; Etters et al., 2008), with caregiver burden exacerbated by the additional issue of managing

incontinence (Etters et al., 2008; Kamiya et al., 2014; Kamiya et al., 2023; Lodewyk et al., 2022; Murphy et al., 2021). Issues associated with lower urinary tract symptoms and toilet problems in caring for the person with dementia are specifically identified as having a significant impact on caregiver burden (Kamiya et al., 2023). Qualitative feedback from care partners of the person with dementia and incontinence, identified *Burdens* as a key factor, with care partners reported as experiencing considerable burdens, fatigue and increased responsibilities that were unique to their role, and a diminishing social life and frustration (Lodewyk et al., 2022).

For item 4 of the ICIQ-Cog-C, participants in the four carer groups reported a low overall mean score for item 4: *'Incontinence is a taboo topic for me and I don't like talking about it'* (Table 15) This consistently reported response may suggest that, overall, carers and professionals are not dwelling on the issue of incontinence but are, instead, seeking support and guidance on the responsibilities, routines and overall management of the person living with dementia and incontinence. The low mean scoring for this question may also be an indication that, for these carers, the job of daily continence care has become somewhat normalised, and they are "just getting on with it" (Drennan et al., 2011, p. 4).

For the EQ-5D-3L, which measures the MOOC research participants perception of their own health status, the overall mean score for the five issues (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) was reported as a *'no problems'* response. This represents a score of 1 out of an overall score of 3. These results indicate that the MOOC research participants were not experiencing issues that they considered to be impacting on their physical or emotional health. The high scoring reported in the EQ-VAS-THT would also reinforce the reporting by the research participants that they were in good health. An important consideration relating to the carers' reported health status in this Project is whether they are representative of the wider population of carers of people with dementia and incontinence. An explanation for the results from the EQ-5D-3L and EQ-VAS-THT could be that the MOOC research participants are a self-selecting population who have the time, energy, and capacity to undertake a MOOC.

7.1 Strengths and Limitations

A key strength of the project was the use of co-design methods to create content for the MOOC. These methods provided an opportunity to explore a much neglected and stigmatised topic. The systematically collected information about carers' information and support needs could reduce a trial-and-error approach to continence caregiving for this population. However, further work is required to ensure the issues identified reflect carer heterogeneity in terms of age, gender, culture, care recipients' dementia severity, care setting, country, and other such key variables.

The major limitation of the project was that there were a lower than anticipated number of online surveys completed at both T1 and T2 by the MOOC research participants. The reasons for the small number of completed online surveys are likely to be varied given the diversity of country of residence but may include factors such as the overall presentation style of the online surveys; the number of questions and scales required to be completed at two time points; 'time-poor' learners; and English as a second language.

Because of the small number of completed and paired T1 and T2 online surveys (seven in total), the Wilcoxon Signed Rank Test (non-parametric paired test - comparing T1 and T2 surveys) were performed for each QoL measure. The reported overall effect size for each QoL measure was small and non-statistically significant. The EQ-VAS-THT was the exception, however, with a moderate effect size reported.

The small number of completed and paired surveys meant that there was limited scope for an insightful interpretation of the findings. Nevertheless, the reported moderate effect size from the EQ-VAS-THT measure may suggest that the MOOC content, which focused on practical and nuanced information and resources around the issues of responsibilities, routines and overall management of the person with dementia and incontinence that is based on dignity and respect, may have positively impacted on the carers' overall perception of their health.

A robust interrogation of the findings from the paired surveys would be enabled with a larger number of completed and paired surveys. Given this, further considerations around the interface between the MOOC

learner and the online survey may be helpful, with issues such as potentially 'time-poor' learners, health literacy, and English as a second language factored into future survey construction.

The limited number of survey respondents also meant we were unable to determine the impact of the MOOC on different users, i.e., to differentiate between the impact on formal carers from informal carers.

It is also important to acknowledge the limitations of the MOOC being available in English language only. This could have resulted in the exclusion of linguistically diverse people and introduced selection bias.

8. CONCLUSION

The project to develop the Caregiving, Dementia and Incontinence MOOC employed a novel method to identify the information and support needs of carers of people with dementia and incontinence. Importantly, in so far as the MOOC was co-designed with people with dementia and incontinence and their carers, the content is informed by an understanding of their diverse perspectives, experiences and expertise. To this end, the MOOC is more likely to be contextually relevant and effective in meeting their needs. We anticipate the information could improve the lives of people with continence care needs, and carers across the world. For family carers, it could augment efforts to support people with dementia to remain living at home as long as possible. The MOOC bridges the gap in education identified by Ostaszkiewicz et al., (2022) and by Edwards et al. (2021).

Information about the MOOC and its outcomes are currently being shared widely with the dementia and incontinence communities in Australia and internationally. A consumer summary has been developed which will be disseminated to key stakeholders as part of a broader dissemination strategy. The future viability of the MOOC is contingent on FutureLearn's business model. Further funding is required to strengthen the MOOC to ensure facilitation is available on an ongoing basis and to add content to ensure the MOOC is culturally appropriate and responsive to the information and support needs of cultural and linguistically diverse populations as well as people who identify as LGBTIQ+ and Aboriginal and Torres Strait Islander people.

The development of this type of knowledge translational resource is particularly timely given the current demand for online learning and support, an ageing population and a rapid increase in the number of people living with dementia. The MOOC is fit for purpose for family carers, as well as RNs, ENs, and Care Assistants working in the aged care sector. It could support and enhance existing education programs that prepare the nursing and personal care workforce. Specifically, it could strengthen quality of communication and continence care for all people with continence care needs and thereby minimise the risk of abuse and dignity violations identified by the Royal Commission into Aged Care Quality and Safety. As noted by Dementia Australia, *'If you can get it right for dementia, you can get it right for everyone else.'* (2019).

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APPENDICES

Appendix 1. Ethics approval: Austin Health

Austin Hospital

145 Studley Road
PO Box 5555 Heidelberg
Victoria Australia 3084
Telephone 03 9496 5000
Facsimile 03 9458 4779
www.austin.org.au



AUSTIN HEALTH HUMAN RESEARCH ETHICS COMMITTEE

ETHICAL APPROVAL

Dr Joan Ostaszkiewicz
National Ageing Research Institute

04 October 2021

Dear Dr Joan Ostaszkiewicz,

HREC Reference Number: HREC/77685/Austin-2021

Austin Health SITE REFERENCE Number: ND 77685/2021

Project Title: Dignity in continence care in people with dementia and incontinence: Translating principles that protect dignity

I am pleased to advise that the above project has **received ethical approval** from the Austin Health Human Research Ethics Committee (HREC). The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007, updated 2018). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007, updated 2018), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

HREC Approval Date: 4 October 2021

Ethical approval for this project applies at the following sites:

Site
National Ageing Research Institute, VIC

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
HREA	1	05 July 2021
Protocol	1	02 July 2021

Victorian Specific Module (VSM)	-	05 July 2021
Letter of Invitation – Focus Group	2	25 August 2021
Letter of invitation – Telephone Interview	2	25 August 2021
Letter of Invitation – Video Interviews	2	25 August 2021
Participant Information Sheet for Surveys	2	25 August 2021
Participant Information Sheet/Consent Form for Focus Groups	2	25 August 2021
Participant Information Sheet/Consent Form for Telephone Interviews	2	25 August 2021
Participant Information Sheet/Consent Form for video interviews	2	25 August 2021
Plain Language Statement for Surveys	2	25 August 2021
Question Guide for Focus Groups	1	25 August 2021
Question Guide for Surveys	1	25 August 2021
Question Guide for Telephone Interviews	1	25 August 2021
Question Guide for Video Interviews	1	05 July 2021

Noted Document	Version	Date
CVs – Alison Hutchinson, Joan Ostaszewicz and Michael Murray	-	-
Project Budget	1	25 August 2021

Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
 - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: **Monitoring and reporting of safety for clinical trials involving therapeutic products November 2016**.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters, which may affect the conduct of the project.
- If your project involves radiation:**

- **It is your responsibility to ensure the research is added to the site Management Licence issued by Department of Human Services – Radiation Safety Section prior to study commencement should it be required (check your Medical Physicist Report). The site RGO must be notified when the research has been added to the licence.**
- **You are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).**

Please note: Template forms for reporting Amendments, Adverse events, Annual/Final reports, etc. can be accessed from: <https://www2.health.vic.gov.au/about/clinical-trials-and-research/clinical-trial-research/how-to-make-an-hrec-application-for-clinical-trials>.

The HREC may conduct an audit of the project at any time.

Yours sincerely,

 Digitally signed
by Jac Kee Low
Date: 2021.10.04
16:26:20 +11'00'

Jac Kee Low

HREC Non-Drug Trials Officer

Office for Research, Austin Health
Level 8 HSB.

E-mail: ethics@austin.org.au

Web: <http://www.austin.org.au/researchethics>

Appendix 2. Ethics approval: Deakin University



Memorandum

To: Prof Alison Hutchinson
School of Nursing & Midwifery
B

cc:

From: Deakin University Human Research Ethics Committee (DUHREC)

Date: 24 May, 2022

Subject: 2022-140
Dignity in continence care in people with dementia and incontinence: Translating principles that protect dignity
Please quote this project number in all future communications

Approval granted by for this project will be noted at the DUHREC meeting to be held on 20/06/2022.

It will be noted that approval has been granted for Prof Alison Hutchinson, School of Nursing & Midwifery, to undertake this project as stipulated in the approval documentation.

The approval noted by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the memo. It is your responsibility to contact the HREC should the project be discontinued before the expected date of completion. You are reminded that:

- The Deakin logo should be on any participant documents, including the Plain Language Statement, or where that is not possible, ensure Deakin University's involvement in the project is clearly written in the documentation
- The Deakin Human Research Ethics Office needs to be notified immediately if any complaints are received
- An annual/progress report must be submitted to the approving HREC and at the conclusion of the project, a final report must be submitted to the Deakin HREC.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).

Human Research Ethics Unit
research-ethics@deakin.edu.au
Telephone: 03 9251 7123

Appendix 3. FutureLearn cost structure

Ways to learn Choose the best way to learn for you!			
	Buy this course \$199/one-off payment Fulfill your current learning need	Best value - learn more, save more! Subscribe & save ~~\$54.99~~ \$37.99 For the first two months. Automatically renews Develop skills to further your career	Limited access Free Sample the course materials
Access to this course	✓	✓	Access expires 7 Aug 2023
Access to 1,000+ courses	✗	✓	✗
Learn at your own pace	✓	✓	✗
Discuss your learning in comments	✓	✓	✓
Tests to check your learning	✓	✓	✗
Certificate when you're eligible	Printed and digital	Digital only	✗
	Continue & Upgrade	Continue & subscribe Cancel for free anytime	Continue with limited access

Appendix 4. Organisations that promoted the MOOC

[Aged Care News](#) – an online publication for aged care related news, research, and discussion.

[Aged Care Research & Industry Innovation Australia \(ARIIA\)](#) - an independent, not-for-profit organisation, set up to lead the advancement of the aged care workforce capability by promoting and facilitating innovation and research to improve the quality of aged care for all Australians.

[Alzheimer's Europe](#) - peak body in Europe to support people with dementia, carers of people with dementia, and to develop national dementia strategies. Alzheimer Europe has 41 member associations from 37 countries.

[Australian & New Zealand Urological Nurses Society](#)

[Australian Aging Agenda](#) - an independent bi-monthly magazine and news website for people who work in or around the broad aged services and retirement living sectors in Australia.

[Australian Nursing & Midwifery Journal](#) - is the monthly journal of the Australian Nursing and Midwifery Federation which is the largest union in Australia with over 290,000 members.

[Class Central](#) – a listing of online education resources based in the USA.

Continence Foundation of Australia – [Bridge Magazine](#) (June 2023)

[Continence Nurses Society Australia](#)

[eLearn Africa](#) – an online source of eLearning for African students. eLearn Africa also has overseas partners and promotes access to online academic programs throughout the world.

[Inside Ageing](#) - Inside Ageing provides news, information and resources for people working in aged care and businesses that support aged care providers.

[The Senior](#) - an online source of news and views to Australia's senior population.

Appendix 5. ICIQ-Cog-P

This measure aims to identify levels of incontinence-related bother - as observed by the carer.

How often in the past two weeks ...

- 1. How often was the person unable to indicate verbally or nonverbally (through specific actions or gestures) that they have experienced an episode of incontinence?*
- 2. How often did incontinence have a negative impact on the person's eating and drinking (avoiding fluid intake)?*
- 3. How often did the person show negative emotions such as anger or disgust during or after an incontinent episode?*
- 4. How often did personal care, change of continence aids, or help with toileting provoke negative reactions in the person (e.g., verbal comments, defensive movements)?*
- 5. How often did incontinence limit the mobility of the person in their daily activities?*
- 6. How often was the person's ability to participate in social activities strongly affected by their incontinence?*
- 7. How often was the person's sleep interrupted by their incontinence?*
- 8. How often did incontinent episodes negatively impact on the person's mood?*

Scoring

- 1 = seldom (1 - 2 times a week)
- 2 = sometimes (5 - 7 days)
- 3 = often (on most days)
- 4 = very often (several times a day /every day)

Appendix 6. ICIQ-Cog-C

This measure aims to identify the level of care efforts - burden on the caregiver

- 1. My caregiving responsibilities are increased by the person's incontinence.*
- 2. My daily routines are dictated by the person's incontinence.*
- 3. People with dementia require significantly more help to manage incontinence than people without dementia.*
- 4. Incontinence is a taboo topic for me and I don't like talking about it.*

Scoring

1 = strongly disagree

2= disagree

3 = moderately agree

4 = strongly agree

Appendix 7. EQ-5D-3L

This measure aims to measure the health-related quality of life of the general population. Please answer these questions with yourself in mind, not the person you care for. Under each heading, please tick the ONE box that best describes your health TODAY.

1. Mobility

- 1 = I have no problems in walking about
- 2 = I have some problems in walking about
- 3 = I am confined to bed

2. Self-care

- 1 = I have no problems with self-care
- 2 = I have some problems washing or dressing myself
- 3 = I am unable to wash or dress myself

3. Usual activities

- 1 = I have no problems performing usual activities
- 2 = I have some problems performing usual activities
- 3 = I am unable to perform usual activities

4. Pain /discomfort

- 1 = I have no pain or discomfort
- 2 = I have moderate pain or discomfort
- 3 = I have extreme pain /discomfort

5. Anxiety/depression

- 1 = I am not anxious or depressed
- 2 = I am moderately anxious or depressed
- 3 = I am extremely anxious or depressed

EQ-VAS-THT (Total Health Today)

Scoring

- 0 is the worst health you can imagine.
- 100 is the best health you can imagine.

Appendix 8. ZBI-12

This measure addresses the health-related quality of life of family carers associated with 'burden' of care. (**This measure is not completed by professional carers and those with no experience as a family carer.)

Do you feel ...?

Q1. That because of the time you spend with your relative that you don't have time enough for yourself?

Q2. Stressed between caring for your relative and trying to meet other responsibilities (work/family)?

Q3. Angry when you are around your relative?

Q4. That your relative currently affects your relationship with family members or friends in a negative way?

Q5. Strained when you are around your relative?

Q6. That your health has suffered because of your involvement with your relative?

Q7. That you don't have as much privacy as you would like because of your relative?

Q8. That your social life has suffered because you are caring for your relative?

Q9. That you have lost control of your life since your relative's illness?

Q10. Uncertain about what to do about your relative?

Q11. You should be doing more for your relative?

Q12. You could do a better job in caring for your relative.

Scoring

0 = never

1= rarely

2 = sometimes

3 = quite frequently

4 = nearly always

Appendix 9. MOOC feedback questions

1. I found the content of the course easy to understand.
2. The videos and internet resources helped me to understand the course content.
3. The course was visually engaging.
4. There were adequate opportunities to ask questions.
5. The information is applicable to my everyday life.
6. The course was culturally appropriate to me.
7. I learnt something of value from the course.

Scoring

1= strongly disagree

2 = disagree

3 = neutral

4= agree

5 = strongly agree